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Date February 28, 1977
Abstract

This thesis explores the cultural construction of women's experiences with breast cancer in Vancouver, British Columbia. After completing treatment for breast cancer women must reformulate their personal biographies to include the diagnosis and treatment. This reformulation includes the reconstruction of self, both identity and body, and of biographical time and takes place within a social context. In this thesis I explore the cultural frameworks that guide these reformulations. I refer to these as breast cancer narratives.

I interviewed 32 women who have completed treatment for breast cancer. There are two sets of data: one set of 29 collected in single interviews, and one set of three collected over multiple interviews. I analyze the interviews looking for common themes and structures from which I constructed breast cancer narratives.

In Canadian society, cancer has been commonly portrayed as a "death sentence". Recently, there has been an attempt to transform this portrayal of cancer to one of a disease which can be survived. The breast cancer narratives include both portrayals of cancer, resulting in an ambiguity about survival. This ambiguity is resolved by constructing a viable discourse of hope for the future.

During the process of diagnosis and treatment the participants learn a discourse of hope which is informed by biomedical culture and focuses on successful treatment. However,
once treatment is complete, the participants are faced with challenges to their construction of hope, stemming from the belief that cancer is a terminal illness. To meet these challenges they modify their discourse of hope.

I identify four cultural schema used by participants to reformulate their personal biographies. These schema link concepts of what may have caused the cancer and the evolving discourse of hope. This multiplicity of schema leave the potential for conflict.

As a result of the multiple schema and modifications to the discourse of hope the constructions of breast cancer are diverse. Therefore there are multiple and conflicting constructions of breast cancer in Canadian Society. This is an important consideration when developing services for women who have had a diagnosis of breast cancer.
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Without the willingness of the participants to share their experiences of having had a diagnosis of breast cancer this thesis would not have been possible. In particular I would like to thank Rebecca, Anne and Trisha for their participation.

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Chapter I - Introduction

Attending to the patient's discourse as it evolves in the course of the illness trajectory enables us to understand relationships between dimensions of human suffering and the cultural and structural context in which they exist. (Kaufman 1988b:350)

This thesis explores the cultural construction of women's experiences with breast cancer in Vancouver, British Columbia. To do this, I focus on how women, who have had a diagnosis of breast cancer\(^1\) and have finished treatment, reformulate their personal biographies to include the diagnosis and treatment in their daily lives. I am interested in the cultural constructs used to develop breast cancer narratives, particularly as they relate to the conceptualization of becoming well or "back to normal" after a diagnosis of a life-threatening disease.

Many more people diagnosed with cancer are surviving through the treatment period than before (National Cancer Institute 1995). Concerns have been raised about the problems people may have in returning to daily life after such a diagnosis (Dow 1990, Hoffman 1989a, Mullan 1985, Quigley 1989). Research has also examined the positive relationship between social support and survival from cancer (Baltrusch and Waltz 1985, Puch and Marshall 1983, Waxler-Morrison et al 1991). I am interested in how a person who has had a diagnosis of cancer conceptualizes the process of survival. Exploration of the boundary between

---

\(^1\) I use the phrase "having had a diagnosis of breast cancer" rather than "with breast cancer," following the work of Juanne Clarke (1985). I do not want to identify the participants in this study as people with cancer, as that suggests cancer is the defining quality for the individuals.
"illness" and "survival" provides insight into the broader domain of the cultural construction of illness and health in Canadian society.

I am interested in breast cancer for two reasons: first, because although a large number of women each year are diagnosed with it and many die, a number survive for a significant number of years after diagnosis (National Cancer Institute 1995); second, because there is an increase in public awareness of, and discussion about breast cancer (Batt 1994; Greene 1992, Soffa 1994).

In this thesis I analyze interviews with women who have had a diagnosis of breast cancer for the way in which they have reformulated their personal biographies (Bury 1982, Williams 1984) to include the breast cancer in their everyday lives.

The story starts with the diagnosis of a cancerous tumour in the breast. When women are diagnosed with breast cancer, they must make difficult decisions about their treatment. These decisions are based on personal experiences and cultural understandings shared in society (Gifford 1986, Gordon 1990, 1991, Salzberger 1976). Also, through their interaction with medical personnel and institutions, these women are exposed to biomedical perceptions and beliefs about women and cancer (Clarke 1985), particularly breast cancer (DeSantis 1979, Saillant 1990). They are confronted with structural manifestations of the politics and economics of the local health care system (Kaufman 1988b). The majority of women going through this illness trajectory are also exposed to alternative discourses about
cancer, from the media and self-help groups for example, and to the structural constraints of daily life.

Once the women have finished treatment, usually about one year after diagnosis, they are no longer cancer patients, but the influence of cancer on their lives can remain profound.

Biomedicine does not generally recognize the experience of ill individuals, particularly women, as being a valid or valued source of information (Kleinman 1988). However, interest is growing in the narration of the illness experience as one way of understanding illness as lived experience (Frank 1984; Good 1994; Kleinman 1988; Brody 1987; Conrad 1990; Garro 1992, 1994; Hughes 1992; Morse and Johnson 1991). The narratives of women who have had a diagnosis of breast cancer relate how this cancer becomes a part of their personal biographies.

In analyzing the narratives, I use the concepts of biographical disruption and repair (Bury 1982, Williams 1984) to highlight the process of incorporation. I found that the participants' life stories are constantly disrupted and repaired as a result of the challenges of living with having had a diagnosis of breast cancer. This process of ongoing biographical repair extends well beyond the treatment period. The challenges faced by the participants can be understood as a contradiction inherent in the cultural understanding of breast cancer.

Cancer is commonly constructed as a "death sentence" (Patterson 1987). However, recently there have been attempts to reconstruct cancer as "survivable" illness (Gordon 1990). In analyzing the personal stories, I found this change of meaning
has resulted in conflicting interpretations of breast cancer. The illness stories undergo constant revision as the participants try to accommodate these contradictory interpretations.

To provide a context for the reader to interpret the narratives I have reviewed in Chapter IV some basic statistics on the incidence, mortality and survival of breast cancer in Canada and British Columbia. These statistics provide some information on the estimated number, in 1995, of women who would be diagnosed with breast cancer and who would die from it. During this research I found that such statistics are used in the cultural construction of breast cancer, most commonly to state that breast cancer is a serious disease. In this thesis I take for granted that breast cancer is serious, as it is life-threatening.

Chapter IV also includes a description of the staging of breast cancer tumours, that is, the determination of the seriousness of the disease. This provides the reader with a basic understanding of the biomedical construction of breast cancer and its treatment. Most participants knew the stage of their breast cancer, and they used this information to evaluate the seriousness of their disease. I have left additional information, such as descriptions of breast cancer treatment to be told by the participants themselves.

Finally in Chapter IV, I have included a brief overview of the health care system and services available to women in the Lower Mainland of British Columbia\(^2\) who have had a diagnosis of

---
\(^2\) The Lower Mainland includes the city of Vancouver, its suburbs and the lower valley of the Fraser River.
breast cancer. Similarities in the illness stories result from the fact that participants had provincial health insurance, which covers most of the cost of treatment, and they all used a centralized treatment facility, where they were exposed to the same institutional culture.

To demonstrate the richness and detail of the stories I have presented in Chapter V the full accounts of two women, Anne and Rebecca. These accounts provide the context, background and individual stories of two women's experiences with breast cancer. Both stories have some remarkable similarities to, and many differences from each other and those of other participants. It becomes clear that breast cancer is not just a medical, but also a social experience. The women must deal with the cancer, which is a threat to their lives, and with the extremely difficult cancer treatments. As well, they have to deal with continuous disruption in social relations and their day-to-day lives.

Chapters VI through VIII analyze the breast cancer accounts as narratives. They include data from the first two interviews and from 30 other interviews. I start in Chapter VI with the analysis of stories of diagnosis and treatment. These stories are remarkably similar throughout all the accounts, because of the participants' interaction with available health services (see Chapter IV) and their shared cultural understanding of breast cancer.

As noted above, in Canadian society cancer is considered both a death sentence and a survivable illness. During the period of diagnosis and treatment, the participants face their
own mortality. They narrate this experience through reconstructing the story of their diagnosis of cancer: moving from facing death to having a disease that can be successfully treated. They construct a future full of hope.

The narrations of this transition are remarkably similar, and are shared with many of the oncologists, surgeons and other treatment personnel. The participants may learn this discourse of hope (DelVecchio Good 1991, DelVecchio Good et al 1990) through the process of diagnosis and treatment.

However, after the treatment period is finished the participants must get on with life. Chapter VII explores how they rewrite their personal biographies to include breast cancer. These accounts of the breast cancer experience are more varied than the stories of diagnosis and treatment. Women fit their experiences with breast cancer into their individual lives.

I found that the participants used four different cultural schemata to construct their narratives and to account for the breast cancer. They include descriptions of the personal risk of getting cancer.

As the participants reconstruct their biographies, they incorporate the discourse of hope. Unlike the story of diagnosis and treatment, the construction of hope differs slightly with each of the schemata used. Therefore, the illness narratives are constantly evolving as the participants move beyond treatment.

Chapter VIII examines the evolving narratives, focusing on how breast cancer becomes a social reality. A diagnosis of breast cancer affects many people besides the women who have been
diagnosed, and therefore affects social relationships (Bury 1982). As well, women who have had a diagnosis of breast cancer are faced with the social, economic and political reality of having a life-threatening illness. All of these realities modify the evolving illness narratives.

The women are faced with challenges to their constructions of the future, such as the possibility of a daughter getting breast cancer. The illness narratives are altered to accommodate these new challenges, leaving the narratives fragmented and full of contradictions.

Throughout these three chapters I show how the narratives evolve to accommodate individual circumstances. Despite the women’s diverse circumstances, the narratives maintain common themes, including an understanding of the personal risk of getting cancer, constructing a viable discourse of hope, repairing disrupted social relationships, and coming to terms with the contradictions of breast cancer. The most significant theme is the last, in that the participants are constantly trying to revise their understanding of breast cancer to accommodate the ambiguities between constructions of the disease as both a death sentence and a survivable illness. This contradiction may be inherent in our cultural understanding of cancer and may be one reason cancer is not openly discussed.
Chapter II - Development of a Theoretical Perspective

This chapter develops the theoretical perspective of the thesis and describes how that perspective is used to analyze the data. The first section explores the literature on illness narratives. The second explores the literature on the cultural construction of cancer, focusing on breast cancer.

A. Narrating Illness

Recently there has been growing interest in the narration of the illness experience as one way of understanding illness as lived experience (Good 1994). This interest has developed from the convergence of two areas: research in medical anthropology on illness as lived experience and anthropological research on narratives and narrative thought. In this section I review this convergence and discuss how, in the case of this thesis, individuals' accounts of their experience with breast cancer are formulated into illness narratives, the intersubjective constructions that position the stories within a social and cultural context. The analysis of these narratives provides insight into the cultural construction of breast cancer.

1. Illness as Lived Experience

The interest in medical anthropology in illness as lived experience developed out of a lack of understanding of the social context of illness and healing in medicine. Until recently, medical, nursing and rehabilitation research on illness tended to
divorce the experience of being ill from that of living in the social world. The ill person was considered a patient. Her existence outside the clinic was not considered relevant to the type of treatment she received, nor to whether or not she recovered from her illness. In cases of chronic illnesses and disabilities this narrow clinical gaze resulted in failures of treatment being blamed on the patient (Zola 1982).

Medical anthropologists and sociologists have long been interested in the social experience of becoming ill and healing. For example, early anthropological work explored how different groups of people explained what caused and healed disease (Turner 1968, Evans-Pritchard 1937). These investigations led to an understanding of the way in which the classification of disease and the treatment of illness reflected worldviews (Levi-Strauss 1963), social relations (Evans-Pritchard 1937) and social processes (Turner 1968). They did not deal, however, with how the ill individuals lived or how their experience was framed by worldviews and social processes, although later anthropologists were more likely to do so (cf. Leyton 1978, Fabrega and Silver 1973).

Theoretical work in medical anthropology and sociology also contributed to the understanding of illness as lived experience. A number of theoretical developments were particularly

---

3 Epidemiological research has demonstrated the importance of variables such as social support to survival and health status (Berkman and Syme 1979). Several studies have linked social support to improved quality of life (Bloom 1982, Bloom and Speigel 1984, Dunkel-Schetter 1984) and survival (Funch and Marshall 1983, Waxler-Morrison et al 1991) of breast cancer patients.
important, such as the initial development of the concept of the sick role by Talcott Parsons (1979). Parsons conceptualized a sick role, with rights and obligations that must be adhered to for healing to occur. This concept grounds the experience of being sick firmly in the social world. A criticism of Parsons' functionalist sick role is that, although it makes sense for time-limited acute illnesses, it does not account for the roles of persons chronically ill or disabled (Gallagher 1979, Alexander 1982).

The second theoretical development was that of a distinction between "disease" and "illness". This distinction allows for the elaboration of the social experience of being sick, where "disease" is the biological and psychological processes that have gone awry with the individual, and where "illness" is the social experience and the meaning attributed to the disease (Kleinman, Eisenberg and Good 1978).

Therefore "illness" can be studied without challenging the assumption that biomedical diseases are generic and universal. This distinction has enabled clinicians to argue for incorporating into treatment plans information on patients' everyday existence with the hope of humanizing medical practice (Fabrega 1979, Kleinman 1988).

---

4 Parsons' sick role has been elaborated to consider being ill not as a role, but as behaviour (Fabrega 1974). Illness behaviour is an expansion of the more traditional sick role, but it still focuses on an episode of illness and on the medical institutions that treat it (Schneider and Conrad 1983), not on the everyday experience of living with illness.
The third theoretical development was Kleinman’s (1980) concept of "explanatory models". Kleinman argues that when an individual becomes ill, he or she holds an explanatory model of the illness. These models include constructs of etiology (time and mode of the onset of symptoms), pathophysiology (course of the sickness) and treatment. They are used to understand the course of the illness, to evaluate the treatment received and to produce social meaning for the illness.

The physician also holds an explanatory model of the patient’s illness, based on a biomedical understanding of disease and physiology. As well, he/she holds a conception of what treatment should entail and what course the illness should take. All of these can differ significantly from the conceptualizations developed by the patient. Kleinman (1980) proposes that teaching medical professionals to elicit patients’ explanatory models will improve their ability to provide appropriate care.

The use of Kleinman’s explanatory models is limited, however, because it was developed within the context of the biomedical treatment system. The constructs included in the model, such as etiology and appropriate treatment, are similar to and derived from biomedicine and do not include any concept of illness as a social experience.

Young (1981) points to another limitation. The explanatory models assume rationality and ignore the complexity of the construction of models of illness. As I found in this

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5 Hahn has developed the concept of "sickness" which he defines as an unwanted condition of self, or substantial threat of an unwanted condition of self (1995:22). This is much broader than the concept of an explanatory model, as it can include
research, an individual's understanding of an illness can contain contradictions resulting from the competing constructions to which the individual is exposed, and in addition their understanding can change over time with new information and experiences (Becker 1994).

Besides these theoretical developments in medical anthropology and sociology, there has also been increasing interest in people living with chronic illnesses and disability. Much of this research is in the tradition of symbolic interactionism, using a grounded theory approach (for example Charmaz 1990, Hughes 1992). This work has contributed to an understanding of the organization and management of daily living with chronic illness (Strauss and Glasser 1978, Morse and Johnson 1991). In the life course of a person with chronic disease, while medical crises do occur and must be managed, the day-to-day reality of working, mobility and maintaining social contacts and family ties demands considerable time and energy (Schneider and Conrad 1983).

However, the process of examining the data for common themes and categories (Glaser and Strauss 1967) limits the exploration of the variation within each category and the analysis of those cases that do not fit the common themes and categories. This

conditions not normally considered medical or health conditions. Hahn describes accounts of sickness that are much like illness narratives.

6 Armstrong (1990) argues that the increased interest in and research on chronic illness by social scientists has extended the socio-medical gaze. The implication is that social scientists doing research may be creating data and medical problems where none actually exist.
categorization and thematic analysis "disembodies" the categories as identified by the researchers from the actual experiences of the individuals who produce the data (Conrad 1990).

An alternative way to examine the illness experience is as part of a personal biography (Frank 1984, Kaufman 1988a), illness trajectory (Kaufman 1988b), therapeutic narrative (Early 1982), sickness story (Brody 1987) or illness narrative (Kleinman 1988, Williams 1984). It is important to distinguish between the account or story of an illness experience and an illness narrative.

It would be a grave error to conceive illness narratives as the product of an individual subject, a story told by an individual simply to make sense of his or her life. . . The narratives were intersubjective in a direct and obvious way: they were stories that utilized popular cultural forms to describe experiences shared by members of a family; the stories were dialogically constructed, told often by interwoven conversations of several persons, stories whose referents were often the experiences of persons other than the narrators; and they were stories positioned amidst authors, narrators, and audience (Good 1994:158).

For simplicity throughout this thesis, I have referred to the individual stories of the experience of having had a diagnosis of breast cancer as stories or accounts. Illness narratives are the abstract cultural constructions, which I draw out of the individual accounts through the analysis of common structures and themes.

2. Narratives and Narrative Thought

The current interest in illness narratives parallels the development in anthropology and other disciplines of an interest
in narratives and narrative thought. An illness narrative is the culturally appropriate story of becoming ill, the treatment of the illness and the recovery. Narratives are used as a way of thinking about the world and understanding what is going on in one's life.

Narrative offers what is perhaps our most fundamental way of understanding life in time. Through narrative we try to make sense of how things have come to pass and how our actions and the actions of others have helped shape our history; we try to understand who we are becoming by reference to where we have been (Mattingly and Garro 1994).

As a form of communication between two or more people, the writer and reader, the speaker and listener, a narrative has a structure (Agar 1980). Labov and Waletzky (1966) examined numerous narratives of events and found a similarity in their basic structure. The similarity of structure was found in the sequencing of events and a referential or evaluative function.

Life narratives share a similar structure, which provides coherence and an evaluative quality to the stories (Meyerhoff 1982, Lawless 1993). The structure of the narrative assists in the communication of the story, providing a framework for interpretation.

The structure of the narrative is formed by the plot, which shapes the story and gives it direction and intent (Brooks 1984). The plot provides a beginning and an end, so there is the sense of the passage of time.

Narrative is one of the ways in which we speak, one of the large categories in which we think. Plot is its thread of design and its active shaping force, the product of our refusal to allow temporality to be meaningless, our stubborn insistence on making meaning in the world and in our lives (Brooks 1984:323).
Narratives not only relate events, but also construct the meaning of those events. They are an attempt to make the inexplicable understandable and meaningful through the incorporation of cultural understanding shared by members of the society (Price 1987; Garro 1992, 1994).

My interest is to analyze women's accounts of their experience of having a diagnosis of breast cancer to illuminate cultural understandings shared by members of their society. The women construct their accounts with a structure and plot to help communicate their stories. The examination of the structure and plots provides insight into the illness narratives women are using.

3. Illness Narratives

In the next part of this chapter I review some of the literature on illness narratives, to explore the themes that provide insight into the cultural construction of breast cancer. First, I review the process of disruption and repair that occurs with the advent of a chronic condition. Second, I review how the concept of disruption and repair can be applied to the self, the body and biological time. Third, I examine the impact of the

---

7 In this thesis I am interested in the narration of illness from the perspective of the individual who is ill. However, there is also a developing literature on the narration of illness from the perspective of the care provider (for example Mattingly 1994, Hunt 1994), which explores many issues of clinical practice. Another fascinating, but as yet small literature is that of anthropologists and sociologists writing autobiographies about their own illness experiences (Murphy 1987, DiGiacomo 1987, and Zola 1982).
social context in which illness occurs on the construction of the illness narrative.

a. Disruption and Repair

The onset of a chronic or life-threatening condition introduces dramatic changes and reshapes an individual's conceptualization of life. The construction of an account of these changes is one way of developing an understanding of what has happened and what may happen in the future. This account

... employs the web of commonsense explanations which links the unique, somatic event with shared cultural knowledge about illness. These explanations serve both to evaluate therapeutic activities and to make sense of experience. They situate illness within the socioeconomic reality which sets the parameters of therapeutic action (Early 1982:1492).

This process of accounting for the onset of a chronic condition within the construction of an illness has been referred to as "biographic disruption" (Bury 1982) or "narrative reconstruction" (Williams 1984).

Incorporation of the pain, suffering, loss, changes and disability of a serious condition into a personal biography can be seen as a process of rewriting or biographical work (Corbin and Strauss 1987, Kaufman 1988a, Williams 1984, Becker 1994). This includes rewriting of life prior to the illness to account for the illness, as well as rewriting future possibilities.

b. The Self, the Body and Biographical Time

Within the research on illness narratives, the concept of disruption and repair has been applied to three areas. They are
the disruption and repair of the self, the body and biographical time (Corbin and Strauss 1985).

The first area addresses the onset of a chronic or life-threatening condition challenges the individual's concepts of self and identity. This occurs through the stripping of autonomy by a disabling condition, such as the threat to life of a cancer diagnosis.

Through the illness story, the individual develops for the listener a preferred identity. In most cases this identity will be one in which the self is able to perform normally and in which life maintains some meaning. Many of these accounts are constructed in ways that are uplifting and optimistic.

Robinson (1990), examining personal stories of people with multiple sclerosis, described how the majority were positive and optimistic. Such positive and optimistic portrayals of self construct a life separate from the illness, where there is hope for the future (Corbin and Strauss 1987). Kaufman (1988a) has referred to this process as the reinterpretation of self.

In their research on women's stories of their experience with breast cancer, Mathieson and Stam (1995) described a series of challenges to identity, resulting in a continuous reconstruction of identity. This suggests a constant challenge to the self, continuing past the initial period of diagnosis and treatment. This is understandable in a chronic illness, where one's condition may deteriorate over time. However, even in an
acute illness, such as cancer, there are times after the completion of treatment when new challenges to the self are raised.\(^8\)

The main challenge to self is the threat of death. However, this specific threat is not raised much in the literature on illness narratives. Saillant (1990), in an extended account of a woman dying of breast cancer, describes the impact of mortality on the illness narrative and the biographical work in reconstructing self. She found the threat of death is a central theme of much of the work on reconstructing of the self and the future. As Yvette went from having cancer to dying from cancer, the meaning of the cancer changed, as did the recognition of the impact on her life.

The self-diagnosis of a cancer "caught in time" [pris a temps] corresponds to the survival experience and is cognitively distinct from the diagnosis of having cancer [avoir le cancer], which is associated rather with the terminal phase. (1990:97)

The threat of mortality posed by a diagnosis of cancer was also the greatest challenge to the individual construction of self for the women I interviewed.

The second area is the disruption and repair of the body. Recently, anthropology has developed an interest in the body as paradigm, for it is through the body that we experience the world (Csordas 1990, 1994; Scheper-Hughes and Lock 1987).

Breast cancer results in physical changes to the body. Some women described how loss of the breast affected their sense of

\(^8\) For the best example of this process of rewriting and rethinking of self, see Anne's narrative in Chapter V.
balance, as they felt off balance or lopsided. Some described how surgery, lumpectomy or mastectomy, had a negative impact on the sexual sensitivity of their breast.

There is also a conceptual change in the individual’s understanding of the body and its limits. With a diagnosis of cancer, the individual's body is seen to have been invaded by cells that are out of control (Seigel 1986). The individual must come to terms with this transgression of the body. Some women redefined their bodies, viewing the breast and the cancer as being outside the body.

The body is a problematic entity, transformed through the narrative.

Meanings associated with an illness are interpreted within this biographical context, through social relationships as well as through the most mundane aspects of life. The body itself evolves within the context of this biography and is transformed in interactions with others (Becker 1994:385).

However, the body cannot be separated from the self (Gadow 1982, Csordas 1994, Turner 1984). The concept of self is formed through the body (Corbin and Strauss 1987). Therefore, in the illness accounts the biographical work of describing the disruption of self is linked inextricably to that of describing the disruption of the body.\(^9\)

Charmaz (1987) argues that the integration of the body and identity makes a successful self and that, through the

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\(^9\) In my personal experience of suffering with a chronic condition I find it difficult to intellectually distinguish between body and self. I have found a gap in language that results in an inability to talk about the physicality of self grounded in the physical body.
reconstructed self, the individual can redevelop hopes and plans for the future. This is the case in the breast cancer accounts, where the physical consequences of treatment are perceived as challenges to identity and self. Reconstruction of self, both body and identity, is necessary to create hope for the future.

The last of the three areas is the disruption of biographical time caused by chronic illness. As a result of this disruption, the passage of time shifts in meaning. Time carries significant and altered meaning within the story. Individuals recount the past in light of the present illness (Garro 1992, 1994; Williams 1984). This is the case in this research, as the women develop accounts of why they got breast cancer or were at risk of getting breast cancer.

Wilson (1991) mentions that as time passes after a diagnosis of cancer, the likelihood of the cancer's recurrence is decreased. Therefore, the passage of time, and marking the passage of time, take on significant meaning in the illness accounts (Roth 1963, Zerubavel 1979). In descriptions of their experiences with breast cancer, the participants in this research mark the passage of time as they pass through a series of check ups with their physicians. The more time that has passed since the diagnosis, as marked by the check ups, the less likely the cancer will recur.

Current time also changes its meaning. Corbin and Strauss (1985) relate how, within the illness account, individuals talk of the importance of the use of time, and that it not be wasted. This is also a prevalent topic in the accounts of the breast
cancer experience. It is as if time has become more important, a limited commodity.

In this thesis I analyze individual accounts of having had a diagnosis of breast cancer, looking for the descriptions of disruption and repair of self, body and biographical time. These descriptions highlight some of the cultural constructs that contribute to breast cancer narratives.

c. Social Context of Illness Narratives

The three areas I have discussed above are all related to the biographical work in the individual accounts. However, the construction of these areas deals with the individual illness stories as if they were isolated from the impact of social relations, economics, politics or institutional medicine. While I have found this analysis insightful, it is also limiting. I believe the analysis must go beyond the individual, to explore other factors that affect the development of an illness account.

Because the women who have had a diagnosis of breast cancer live within society, their illness stories reveal more than just the reconstruction of self and identity. They also include, and must account for, the limitations the individuals face when living with a chronic illness, such as limitations of treatment (Kaufman 1988b) and conflicting interpretations of illness (Blaxter 1983, Wardlow and Curry 1996). This section of the chapter looks at the social context: how it affects the development of illness stories and how it is included in illness narratives.
The first area I wish to raise is the disruption of social relations by the advent of a chronic illness.

My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves the recognition of the worlds of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support (Bury 1982).

Bury (1982) aligns the disruption of biography by chronic illness with a disruption of social relations. This disruption allows for the mobilization of resources in order to deal with the daily management of an ill person’s life. For example, Wilson (1991) documented the extensive amount of work undertaken by husbands when their wives go through chemotherapy. The mobilization of social resources may come from unexpected sources, such as friends or neighbours who were not previously close (DeSantis 1979). Illness may result in expected sources of support not living up to the expectations of the ill person (Bury 1982, Peters-Golden 1982), such as friends who do not visit or help during the treatment of the cancer (DeSantis 1979).10

The second area of disruption is that caused by a declining ability to work and the economic impact of the illness. After an analysis of the illness stories of those facing end stage renal failure, Gerhardt said, "One may conclude that structures of everyday socio-economic coping extend into and characterize also

10 Similar incidents of lack of support have been found among the unemployed (Strother and Bogden 1988).
the lives of those who are chronically sick" (1990:1221).

This is more than just a readjustment of self, although identity plays a major part. It is also coming to terms with the economic consequences of the illness. Feldman's (1986) research has shown that women in the workplace who have had a diagnosis of cancer sometimes face job discrimination. The economic consequences of chronic illness also challenge the storyteller's construct of self, especially in a society where work defines the individual. These consequences will also leave the individual having to cope with declining resources while managing a chronic condition.

The third area of disruption is that caused by the limits of biomedicine. Kaufman (1988b), in her work on the narratives of stroke victims and their caregivers, found that many of the expectations for recovery were limited by the limitations of medicine. The knowledge base or the resources were not available for the individual to obtain the hope for degree of recovery.

The structure and resources available through the medical system can affect both the individuals' stories of their illness and the cultural illness narratives (Anderson 1986). The effect of the medical systems limits and structure on the generation of an illness account is important in the analysis of illness narratives. In Chapter VI of this thesis I show how health service delivery produced a consistent structure, both in the women's stories and in the cultural narratives of breast cancer.

While individuals live with a chronic illness, they are exposed to conflicting interpretations of their illness.
Mathews et al (1994) found, through the illness accounts of black women with advanced breast cancer in the southern United States, that the women modified their own models to account for new information and conflicting interpretations. In some cases, when the woman's model was in conflict with that of the care provider, the woman would terminate her treatment.

Lay beliefs about cancer and cancer treatment are widely held but not widely researched (Mathews et al 1994; Saillant 1990; Balshem 1991, 1993). DiGiacomo (1992) has noted that popular beliefs and biomedical beliefs about cancer, and other illnesses, are not as different as assumed. The study of popular beliefs provides insight into knowledge shared by members of society. Paying attention to stories of conflicting interpretations provides insight into the cultural construction of breast cancer in North America.

In this thesis I analyze the participants' breast cancer stories. I pay attention to their descriptions of the disruption and necessary repair of life, including talk about self, body, biographical time, social relations and structural limitations. Individual accounts about living with illness provide insight into similarities and shared themes, while maintaining the perspective and issues of the individual. While each story is unique, analysis of the shared themes provides insight into breast cancer narratives and the cultural construction of breast cancer in North America (Price 1987, Garro 1992, 1994).
B. Cultural Construction of Cancer

The culturally constructed meaning of the attribution of risk, cause and appropriate treatment of breast cancer affects the individual experience of living with the disease. A woman with breast cancer is exposed to a variety of discourses on the causes of the disease (such as age, reproductive history, genetic predisposition and personality) and the appropriate treatments (such as surgery, chemotherapy, radiation therapy, visualization, relaxation, and lifestyle and diet modifications). Once a woman has finished treatment and is disease free, she returns to a "normal" daily routine as if the disease never occurred, even though she may be asked to provide expert knowledge to others or be involved in organizations that focus on breast cancer.

Medical anthropology, like the rest of the discipline, has developed an interpretive approach (Geertz 1973, Marcus and Fisher 1986, Clifford and Marcus 1986, Keesing 1987).

. . . interest in the contextualization of content within cultural and symbolic studies was represented by a renewed interest in discourse and interpretation, in the interrelationship of semantics and pragmatics, and in the relationship of cultural forms to social praxis and the social construction of reality. (Good and Good 1981:178)

The interpretive approach includes the use of the social constructionist theoretical perspective. From this perspective, diseases are part of a human being's construction of her or his reality (Berger and Luckman 1967). This is very different from biomedicine, where diseases are defined as generic and universal.

Social construction in medical anthropology and sociology is an elaboration of theories of social labelling and the
medicalization of everyday life. Social labelling argues that the label of having a disease and the use of that label legitimates the illness and the treatment the individual receives (Waxler 1981a, 1981b). The increasing use of medical labels has resulted in the medicalization of everyday life. More and more of our everyday life is becoming the domain of medicine and medical intervention (Illich 1975).

The social constructionist perspective allows for the examination of the social and historical context of the creation of medical labels and the process of medicalization. Much of this work has examined the "authoritative" discourse of biomedicine. The best known work in the field is Foucault's (1975) analysis of the transition of the "gaze" of medical practice from the whole body to organ systems. Recent medical anthropology in the social construction of health and illness has included work on the representation of social relations in medical encounters (Armstrong 1982, Taylor 1988), the historical development of disease categories (Gabbay 1982, Kaufert 1988), the discourses on the treatment and cause of disease (Young 1980, Susser 1988) and the development and control of medical knowledge (Gordon 1988, Koenig 1988).

Anthropologists agree that "illness categories and disease are culturally constructed" (Lindenbaum and Lock 1993:3). Illness categories and disease, including those of biomedicine, are part of a cultural system. Gaines (1991) makes a distinction between culturally constructed knowledge and socially constructed knowledge in medical anthropology. The basis of this distinction
is that cultural construction is an anthropological enterprise based in the interpretive tradition of anthropology.

The constructivist perspective takes culture history, meaning, human agency, human experience and responsibility as focal, not ephemeral, concerns. It seeks to locate contemporary illness experience in continuous cultural historical processes which serve to frame, interpret and give meaning to experience (Gaines 1991:236).

The strength of cultural construction is that it allows for multiple constructions of an illness or disease to exist in different cultural systems at any point in time. An example is Kaufert and O'Neil's (1993) article on the different constructions of the risks involved in childbirth by Inuit women, epidemiologists and clinicians in Northern Canada. Among the illness stories presented in this thesis are multiple constructions of breast cancer. This variation allows for an understanding of how individual circumstances affect construction of the illness experience.

1. Cancer Metaphors

The "illness experience is articulated through metaphors" (Kirmayer 1992:323)\(^\text{11}\). Metaphors provide a way of understanding one type of experience in terms of another set of experiences (Lakoff and Johnson 1980). Therefore, in this thesis much of the cultural construction of breast cancer will come from exploring

\(^{11}\) It is interesting to note that illnesses have been used as metaphors to describe changes in society (Sontag 1978). Negative elements, such as crime, that are portrayed as growing out of control are described as being a cancer of society. Metaphors are also used in biomedicine, such as the human body being described as a machine (Osherson and AmaraSingham 1981).
metaphorical descriptions of cancer and the cancer experience.

The predominant metaphor, although not always discussed, is that of a diagnosis of cancer as a death sentence (Patterson 1987). The fear of death is the predominant feature of breast cancer stories. It also provides a starting point for an understanding of the generation of other metaphors used to describe the cancer experience.

In North America military metaphors are used predominantly to describe both cancer and its treatments (Sontag 1978). Kleinman (1980:108) points out that war metaphors have been incorporated into western biomedical discourse since the Hippocratic Corpus. Examples specific to cancer include the familiar slogan of the Canadian Cancer Society that "Cancer can be beaten" and the declaration of the "War on cancer" by the United States of America in the National Cancer Act of 1971 (Erwin 1987, Patterson 1987).

Erwin (1985, 1987) discusses the effect of military metaphors and terminology in cancer treatment on the construction of cancer. Cancer is seen as the enemy. Doctors are the leaders in the war and offer hope of victory. Treatments are the doctors' arsenal. The patient is the soldier, putting up a good fight and trying not to let his/her fear show to family members or others.\(^{12}\)

Therefore, the therapeutic ritual of medical militarization is a cultural adaptation for patients and family members to manage the cancer experience, to

\(^{12}\) DeSantis (1979) found that the women in her study tried to put on a brave face when others, especially family members, were seen as being worried. I found a similar strategy described by the women I interviewed in 1987.
become a part of the courageous army fighting the enemy cancer, maintaining as many normal roles as possible, and becoming an "inspiration" for other patients and people in the community. (Erwin 1987:213)

Erwin (1987) describes militarization as a "cultural adaptation" of the patient, family and physician for managing the cancer experience.

The use of military metaphors provides the possibility of victory. This is part of the attempt to change the meaning of cancer from a death sentence to a survivable disease (Gordon 1990). This change has been reflected in a growing literature that talks about the concerns of cancer survivors (Dow 1990, Hoffman 1989a, Mullen 1985), as well as in the popular discourse on cancer treatment (Seigel 1986, Cousins 1989, Simmonton et al 1978, Cunningham 1992). It is also seen in the growth of support groups and other services for cancer survivors and their families.

a. Construction of a Discourse of Hope

Stemming from this use of military metaphors, with the inherent possibility of victory, is an element of hope for a cure, or at least for a future life worth living. This concept of hope is not only present in the popular discourse on cancer, but also in the biomedical discourse. DelVecchio Good (1991, DelVecchio Good et al 1990) found in a study of American oncology that the biomedical discourse on cancer contains a particular construction of "hope". Hope is defined simplistically as the patient's positive attitude, fighting spirit and co-operation with therapy. This meaning of hope is grounded in a popular
construction of the relationship between mind and body, where the power of thought can influence the functioning of the body, in particular by strengthening the immune system (Cousins 1989, Cunningham 1992). When questioned about how they maintain hope in their patients, the oncologists in Good's sample indicated the importance of establishing a partnership with their patients, so they can participate fully in the treatment protocol. This partnership demanded a certain level of physician disclosure, especially for those treatments that were toxic and could have serious side effects. But full disclosure, particularly when prognosis was poor, was not always seen as therapeutic.

Although disclosure of information is seen as being central to maintaining hope in the United States, this is not the case in other countries. In Japan (Long and Long 1982) patients with terminal cancer are not told they have cancer, although the families are told the prognosis.\(^\text{13}\) This is attributed to the Japanese construction of dying. Dying "well" is dying quietly, whereas a death from cancer is conceived as being prolonged and painful (Long and Long 1982).

In Italy (Gordon 1990, 1991; Gordon et al 1991) as well, patients are not told they have cancer. Gordon argues (1990) that, because cancer is seen as terminal, informing a patient would be tantamount to proclaiming them socially dead. Gordon

\(^{13}\) This does not mean that patients do not know they have cancer and are going to die, but rather that they are never told and do not talk about it (Long and Long, 1982). Kleinman (1988) relates a story of going to visit a friend, a Taiwanese physician who Kleinman knew was dying of cancer. The friend, even though he was a doctor, never spoke about the cancer and acted as if he did not know the diagnosis.
cautions that total patient disclosure of cancer diagnosis and prognosis is an American cultural construction, and in the Italian context it would be devastating for the patient.

In a provincial capital in southern Mexico, Hunt (1994) found that physicians engage in an extreme form of disclosure, which is extremely frank and blunt. The physicians claim this frank disclosure persuades patients of the necessity of undergoing prohibitively costly and sometimes unavailable treatments. As well, the frank and authoritative manner of disclosure may be exaggerated because of class differences between physicians and patients and the limited prestige of the medical profession and biotechnology in this particular context (DelVecchio Good et al 1993).

In Canada, as in the United States, there has been a change in the popular and biomedical discourse from cancer as being a death sentence to cancer as being survivable.

For Yvette Tremblay, cancer as a symbol of death was remote from her experience at the time. By counting herself among those persons whose cancer had been "caught in time" [pris a temps], Yvette Tremblay became a "survivor" after her surgery. Quite distinct in portrayal from the terminal phase, survival provides the locus for the new discourse of cancer. This new discourse is accompanied by certain tactics in exchanges between patients and practitioners (Saillant 1990:88).

Changes in discourse promote the development of new metaphors surrounding the concepts of survival and hope for the future.

b. The Causes of Cancer

The cultural construction of cancer contains two other prominent themes in both the biomedical and popular discourses:
the risk of getting or dying from cancer and the causes of cancer. The study of beliefs about the causes of illness is the basis of ethnomedicine and has a long history in medical anthropology (Young 1982). However, the study of the perception of risk of getting an illness is much more recent.

The perception of risk is constructed within a particular cultural framework in that "... the cultural processes which select certain kinds of dangers for attention work through institutional procedures for allocating responsibility" (Douglas 1985). In the illness narrative, the construction of being at risk is one way of accounting for the personal experience of illness.

Gifford (1986) has identified a distinction between epidemiological, clinical medical and popular concepts of the risk of getting breast cancer. For the epidemiologist, the risk of getting breast cancer is "... an objective, scientific concept which describes relationships within large populations" (Gifford 1986:238).

For the clinical medical practitioner risk represents an uncertainty of diagnosis, which can be manipulated and controlled through treatment of the individual or the diseased organ. Gifford (1986) argues that this clinical medical concept of risk predominates in both the practice of medicine and clinical research. This predominance has the effect of medicalizing risk and directing the clinical gaze toward the treatment of the individual rather than examining cancer risk in the broader historical, social, political and environmental context.
Gifford (1986) identified the popular concept of the risk of getting breast cancer as grounded in the personal experience of having symptoms that may be linked to current or future ill health. Other researchers (Dornheim 1991; Balshem 1991, 1993) have also found that popular concepts of the risk of getting cancer are related to the individual experience of having symptoms or of knowing someone who has the disease. In this way, the risk of getting an illness is linked to the understanding of what may cause a particular illness. The causes of illness are culturally constructed and expressed metaphorically.

As with the construction of hope, explanations of the risk of getting cancer vary cross-culturally. For example, Dornheim (1991) found that in Germany, cancer has been attributed characteristics of tuberculosis, such as being "infectious" and "hereditary". The resulting behaviour is to try and distance oneself from anyone suffering from cancer, to hide visits to the doctor for check ups and to not disclose a diagnosis of cancer.

In the United States, DeSantis (1979) found that, although women were concerned that their daughters would also get breast cancer, there was no concern about contagion or infection.

In a study examining middle-aged women's concept of disease in Scotland, Blaxter (1983) found that cancer was discussed without attributing a cause. She concluded that cancer was a dreaded disease and speculation on the cause was "... not only fruitless, on the whole, but also uncomfortable" (Blaxter 1983).

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14 I found a similar concern among the women I interviewed in 1987.
Mathews et al (1994) found a similar situation among black women in the southern United States, where the cause of cancer was not of much interest. In these cases, there is a preference for considering the cause of cancer as being random. The women gave the impression of preferring to believe that cancer was quite randomly caused: "it could happen to anyone". But while they firmly rejected any idea of responsibility, part of the terror of the disease was simply that it was mysterious (Blaxter 1983:66).

Two studies, in England (Cornwall 1984) and the United States (Balshem 1991, 1993) of working class communities' beliefs in the causes of illness found a different perception of the cause of cancer. In both studies cancer was seen as being present in a minute form in everyone, requiring only some kind of trigger to start it growing. These triggers could be an injury or a stressful period of life.15

The most common explanation of cancer in public theories however, involved a combination of internal predisposition towards the disease and some kind of external "trigger" or shock which precipitates onset of disease. Many people expressed the view (attributed to cancer) that everyone has cancer and cancer patients are simply the unlucky ones in whom the disease is activated (Cornwall 1984:158).

It is interesting to note that Cornwall found one of the triggers noted was medical intervention; medicine was seen to be a threat to health. In other studies, concern was expressed that surgery in particular could contribute to the spread of cancer (Mathews et al 1994, Gregg and Curry 1994).

Environmental carcinogens as a cause of cancer seem to be a growing concern. Patterson (1987) noted that this concern began

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15 Young (1980) has looked at the development of the concept of stress as a cause of illness.
in the late 1970’s. A number of studies indicate that people attribute cancer to the physical environment (Salzberger 1976, Dornheim 1991), but for the most part the causes of cancer are linked more to the individual.

Chavez et al (1995) did research on the concepts, among four different ethnic groups in the United States, of the risk and causes of breast and cervical cancer and compared them with the concepts of physicians. They concluded that there are multiple cultural models of risk. They found that Mexican and El Salvadoran immigrants held models widely divergent from those of physicians, that Anglo women’s models were the closest to those of physicians, and that Chicano women’s models fell somewhere in between. Of interest is that models of the risks and causes of breast cancer are embedded in a cultural context, much like those of other illnesses.

In the popular discourse, the risk of getting cancer is often attributed to personal characteristics such as smoking, diet, general health and personality\(^\text{16}\). Through the attribution of risk to personal characteristics, risk becomes individualized, much as it is in clinical medical practice. Individualizing the risk of getting cancer transforms a disease uncontrollable by medical technology into one that the individual can control. The control comes from the ability of the individual to change

\(^{16}\) Sontag (1978) describes the different personality types that were linked to cancer and tuberculosis in the beginning of the century. Tuberculosis was linked with the sensitive and artistic person and cancer with the person who repressed their emotions and anger (see also Canadian Broadcasting Corporation 1990).
personal characteristics and therefore to alter the risk of getting or dying from the disease.

Balshem found that, despite relating risk to personal characteristics, individuals would often refer to the defiant person who "... smoked two packs of cigarettes a day, ate nothing but lard and bread, never went to the doctor, and lived to the age of 93" (1991:162). These same individuals were attributed the characteristics of hard workers who kept a positive attitude, not dwelling on illness. This could be thought of as a link to the biomedical theme of hope discussed earlier: the ability to fight against the odds and maintain a positive outlook.

The concept of risk is individualized in both the biomedical and popular discourses. Individualization may provide cancer sufferers, their families and medical practitioners with the hope that cancer can be controlled through intervention in the personal world. However, this discourse of hope also reduces the understanding of the social, political and economic contexts of cancer.

... the role of 'stress', diet or physical environment in the incidence of cardiovascular disease or cancer is conceived of in such individualized terms as 'personality' and 'life-style'. Such reductions not only extend the moral orbit of medical jurisdiction and shift the culpability of illness more securely upon the victim; they also preclude adequate consideration of deeper socio-cultural processes of which 'stress' and 'unhealthy habits' are but symptoms. (Comaroff 1982:62-63)
c. Uncertainty and the Future

As noted earlier, interest in the survivors of cancer is growing in North America. Survival becomes an issue after treatments have been completed. Then the person who has had a diagnosis of cancer is expected to continue life on his or her own, to get back to "normal". This is also the case with many other chronic illnesses, such as arthritis (Bury 1988, Wiener 1975). Individuals develop strategies for presenting themselves and their lives as normal, or back to normal. However, after a diagnosis of cancer, life is never really the same as before, because of the chance of a recurrence of the cancer which results in uncertainty about the future. Comaroff and Maguire (1981) described parents' anxiety each time their children with leukaemia went in for tests. They felt hopeless and frightened. The future was uncertain. The uncertainty created problems, such as an inability to plan and feelings of vulnerability, as well as opportunities to refocus priorities and change the direction of one's life (Quigley 1989).

Oncologists deal with the uncertainty of cancer by focusing the patients' concerns on the present rather than the future (DelVecchio Good et al 1994). They do this through a restructuring of time. In this thesis the participants restructured or rewrote personal time in a similar way through the use of metaphors about the importance of the present compared to the unknown of the future.

Much of the popular literature on surviving a diagnosis of breast cancer consists of stories about making the best of this
uncertainty, making changes in one's life or just living life to the fullest (Ralph 1994, Rollin 1976, Williams 1993, Crowie 1994, MacPhee 1994). This discourse is one of creating hope for the future. It is optimistic and looking to a future full of life. The model of hope for the future is constructed within a particular cultural context, and one would expect that, as with the models of risk, there would be multiple models.

C. Conclusion

In this thesis I analyze the breast cancer stories presented within interviews of women who have had a diagnosis of breast cancer. Although each individual's story is unique, common structures and themes run throughout (Garro 1994). The cultural construction of cancer is represented in these commonalities. In the analysis I look for these commonalities in four main areas.

The first is the narrative structure of the story. I am most interested in the case where the narrative structure elaborates a shared understanding about the experience of having had a diagnosis of breast cancer. This occurs in the elaboration of the story of diagnosis and treatment in Chapter VI.

The second area is the use of the concept of disruption, repair and biographical work (Williams 1984, Bury 1982) to think about the important themes presented in the breast cancer accounts. I look for the reconstruction of self through the

17 I do not analyze the narratives as speech acts, but rather analyze the content of the narratives.
reconstruction of body and identity and the reconstruction of biographical time. I also look at the social context in which the storyteller exists and how this affects construction of the story. In particular, I examine the disruption in social relationships caused by the illness (Bury 1982) and the limitations imposed by such factors as economics and biomedicine on the ability to reconstruct self and time (Kaufman 1988b).

The third area of focus is the metaphors used in the stories. Much biographical reconstruction is done through the use of metaphors. This is particularly relevant with cancer. Of particular interest is the use of the metaphors of cancer as a death sentence and "cancer can be beaten", and whether this inherent contradiction is resolved.

The final area is how women who have had a diagnosis of breast cancer construct models of hope for the future, risk and cause, and how they deal with uncertainty. I am particularly interested in how the women link these concepts together to form stories that have some coherence.

The analysis of common narrative structures, metaphors and themes in the stories provides insight into the structure and content of breast cancer narratives. These narratives are presented in this thesis.
Chapter III - Research Methods

Researching the experience of women living with a diagnosis of breast cancer I interviewed 32 women who have completed treatment for a primary diagnosis of breast cancer. There are two sets of data. The first set contains 29 open-ended interviews done with women who had completed treatment for the disease at least one year after diagnosis and who had no further evidence of the disease (Waxler-Morrison et al. n.d.)\(^{18}\). These participants had been diagnosed with cancer but have a good prognosis, Stage I or II disease (see Chapter IV).

This sample was limited to women who lived in the Lower Mainland\(^{19}\). The 29 participants came from a stratified random sample selected from the records of the British Columbia Cancer Agency, Vancouver Clinic\(^{20}\). The Vancouver Clinic treats all women in mainland British Columbia who require radiation treatment, as well as many who do not.

The sample was stratified by time passed since completing treatment. Nine women were selected from those who had completed treatment. Nine women were selected from those who had completed treatment.

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\(^{18}\) These interviews were done as part of "Cancer Survivorship: The Psychosocial Experiences in Breast Cancer" conducted by Dr. N. Waxler-Morrison (principal investigator), Dr. T.G. Hislop and Mr. R. Doll (co-investigators) and funded by the British Columbia Health Research Foundation Grant No. 170(92-1). I was the project coordinator.

\(^{19}\) The Lower Mainland includes the city of Vancouver, its suburbs, and the lower valley of the Fraser River. This was done to reduce interviewer travel costs and time.

\(^{20}\) Thirty interviews were completed. However one participant declined to have the interview taped and since the interview was by the other interviewer, I did not include it in this analysis.
treatment up to one year before selection, ten from those who had completed treatment two to three years before, and ten from those who had completed treatment four to five years before. The sample was also stratified by age, with 13 women being under age 50, and 16 over age 50 at the time of diagnosis.\(^{21}\)

The procedure for contacting participants began with the identification of women eligible to participate from a review of charts at the British Columbia Cancer Agency. Fifty-one women were identified.

A letter was sent to each woman's doctor to inform him/her about the research and to check that the woman was still disease free. Doctors identified three women who have had a recurrence of their cancer. These women were excluded from the sample.

Then a letter was sent to the remaining women, describing the project and including a consent form they could return if they wanted to participate. Women who were not heard from received follow-up phone calls. Three women had moved and could not be located.

Fourteen women chose not to participate in the research. Some of the reasons for not wanting to participate included being

\(^{21}\) This sample is still slightly biased toward those women under 50. There are more cases of breast cancer in women over 50 than under 50. Estimated new cases of breast cancer in Canada in 1995 for women 49 and under are 4,130 and for women 50 and over is 13,600 (National Cancer Institute of Canada 1995). In this research it was easier to find and recruit younger women than older women.

\(^{22}\) This is a standard procedure with research protocols at the British Columbia Cancer Agency (Hislop, personal communication).
unwell, being too busy or not wanting to talk about their experience.

As half the women in the sample were over the age of 50 and had multiple health problems, it was expected that some would choose not to participate because of ill health, although a number of the participants in the research did have health problems unrelated to the cancer diagnosis.

Many of the participants said they did not talk much about their diagnosis any more. Getting over the diagnosis and getting on with life was an important part of healing. This may have resulted in some women choosing not to participate.

It was to my advantage to be able to use a random sample of participants, as I was able to interview women who had a broader range of experiences than if I had had to sample women in another way, such as requesting participation through a newsletter or support group. Many of the participants indicated they did not participate in support groups or subscribe to newsletters from various organizations dealing with breast cancer. I would have had no way of reaching them to participate in this research project.

This research focused on the construction of cancer in mainstream culture and did not focus on ethnic minorities. The majority of the participants came from European backgrounds.

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23 In a study of testicular cancer, participants were recruited through a "snowball technique", starting with patients from oncologists' offices and from announcements and advertisements (Brodsky 1995). The participants in this study used predominantly what I have referred to as cancer as a point of change schema, and showed much less variation.
There was one Asian and another from Latin America. Also, the majority were from the middle socio-economic class, with a few being from a higher socio-economic class. It is important to do research on mainstream cultural perceptions before going on to study other ethnic groups. Otherwise, biomedical constructs of disease are used as a point of comparison and almost given a truth value, and popular constructs are ignored (DiGiacomo 1992).

I was one of two interviewers. I conducted 20 of the 29 interviews, and the other interviewer did the rest. The majority of the interviews took place in the participants' homes. Those participants who invited us into their homes treated us like guests, offering tea, coffee and something to eat.

Four interviews were done at the Vancouver Clinic of the British Columbia Cancer Agency. Most often we were able to use the room in the Family and Patient Services Department where support group meetings are held, which was in a different area from the examination and treatment rooms.

The interviews were open-ended, leaving the participants to talk about their experiences. The interviewers usually started by asking, "When were you diagnosed with breast cancer? Could you tell me what happened?" This provided the opportunity for the participants to tell their stories of diagnosis and treatment.

After telling their stories, the participants were encouraged to talk about what had happened since they had completed treatment. A number of topics were introduced by the interviewer if they did not come up during the conversation (see
Appendix I), including relations with family and friends, job experiences, relations with health professionals, personal concerns and health. Any other subjects brought up by the participants were also explored.

The interviews lasted anywhere from one hour to well over two hours. They were audio-taped and then transcribed. I had access to the audio-tapes, transcripts and fieldnotes from all 29 interviews for this analysis.

The second set of data consists of three in-depth case studies recruited through a post-treatment support group run by Patient and Family Services at the British Columbia Cancer Agency for women who have had a diagnosis of breast cancer. I did all of these interviews.

Sue Cannon (1989) wrote about the moral dilemmas of interviewing women with breast cancer. Unlike the participants in Cannon's work, most of these participants had a good prognosis and were relatively well at the time of the study. We were not faced with an impending death. As well, the contact period was much shorter and relationships did not become as close.

However, the question remains about the potential bias of interviewing women, especially when they may see the interviewer as coming from an institute from which they have received care

24 Originally there were four case studies. However, one participant withdrew from participation due to health problems resulting from her treatment for breast cancer.

25 I obtained permission from the British Columbia Cancer Agency to conduct this research. Liz Dohan assisted me with the recruitment by handing out letters at the support group (see Appendix III).
and from which they may need care in the future. In some cases the participants, such as Trisha, freely criticized the treatment they had received, but the majority had nothing but praise for the British Columbia Cancer Agency.

These three in-depth case studies lasted from four to seven hours each, and each included at least two repeat interviews. The interviews were done about a month apart. I did the interviews with Anne and Trisha at their homes, and the interviews with Rebecca in my home. All of the interviews were audio-taped. I listened to the tapes of each interview prior to the following interview and identified areas I wanted to discuss further. The participants all received copies of the tapes of their interviews. They also proofread the transcripts of the excerpts from their interviews included in this thesis.

I included the in-depth case studies to provide a depth of information not available in the shorter interviews. As they were done after the shorter interviews, I was also able to explore further some of the concepts developing from the shorter interviews. Only two of the case studies, Anne and Rebecca, have been included in full, as Anne and Trisha's stories were similar.

Another advantage of the in-depth case studies was that by doing multiple interviews with three individuals, I obtained a perspective on how their stories changed over time. The concept of an evolving account is very important in the understanding of breast cancer narratives and is probably best exemplified by Anne.
The analysis of all the interviews was done through a process of reading and immersion in the interviews, drawing out the sections where participants talked about their experiences with breast cancer or cancer in general. Then I examined these sections of the individual accounts for common themes and structures. From these themes and structures I constructed the breast cancer narratives presented in this thesis.

I analyzed the interviews by drawing out narratives rather than categorizing and/or quantifying themes. This analysis has several strengths. It avoids the fixing of meaning in the development of normative categories (Almeida-Filho 1991, Kaufert 1988, Rubinstein and Perloff 1986). It allows identification of multiple schemata within the narratives. It shows how the breast cancer narratives change with the passage of time. Examining the individual accounts as they developed in the interview also highlighted the inconsistencies and contradictions that are integral parts of illness narratives.

During the interviews, participants mentioned sources of information on breast cancer other than their physicians. I tried to locate as many as I could. They included books (Seigel 1986, 1990; Simmonton et al. 1978; Love 1990; Sontag 1978) and videos (Jillian 1986, Landsbury Company 1988). Many of the participants indicated they read articles from newspapers and magazines, as well as popular literature on breast cancer, but did not specify the exact material. Therefore, I collected and examined some of the popular literature on breast cancer. I collected pamphlets and newspaper and magazine articles from a
variety of sources, such as British Columbia Cancer Agency, information fairs, local supermarkets and newspapers. I also read a number of individual accounts of breast cancer.

A significant amount of popular literature is available on breast cancer specifically and on cancer generally. It ranges from ideas about healing and treatment (for example Seigal 1986, Simmonton et al 1978) to stories of personal experiences with breast cancer (for example Wadler 1992, Rollin 1976).

I also tried to keep abreast of the issues that arose during the period of the research. These included the discussions around a genetic basis of breast cancer (Canadian Breast Cancer Research Initiative 1994) and the controversy surrounding the results of the National Breast Screening Study (Bryant 1993; Caines et al 1993; Miller 1993a, 1993b).

I also did participant observation at a number of public fund-raising events for breast cancer in the Lower Mainland. During this period many of these events were put on by the newly formed Canadian Breast Cancer Foundation - British Columbia Chapter. Events included informational meetings, fund-raising breakfasts and fund-raising runs.

While this research was in progress, a number of local (Ralph 1994, McPhee 1994, Crowie 1994) and other Canadian (Batt 1994, Williams 1993) stories of women's experiences with breast cancer were published. As well, an informational text for patients was published by local physicians (Olivotto, Gelmon and

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In 1994 I became a member of the Scientific Advisory Committee of the Canadian Breast Cancer Foundation - British Columbia Chapter.
Kuusk 1995).

A number of limitations are inherent in the methods used in this study, due to availability of data and resources. As there were no funds for translation or travel, I spoke only to women who were comfortable and confident in English and who lived in the Lower Mainland. The stories of those women who do not speak English and live outside the Lower Mainland, especially the interior and northern British Columbia, would be well worth considering for future research.
Chapter IV - Background Information

This chapter reviews some background information, to assist the reader in placing the interviews in context. This includes a review of some of the statistics on breast cancer, an explanation of the staging of breast cancer tumours, and information on the health care services available to women in the Lower Mainland of British Columbia who have had a diagnosis of breast cancer.

A. Breast Cancer Statistics

These are the most basic statistics, just to provide the reader with an idea of the prevalence of breast cancer in British Columbia. In 1995 the National Cancer Institute of Canada (1995) estimated that in that year, 17,700 new cases of breast cancer would be diagnosed in Canada, and that 5,400 women would die from the disease. For British Columbia the estimates were 2,600 new cases and 630 deaths (National Institute of Canada 1995).

The relative breast cancer survival rate after five years is 73%. This is much higher than lung cancer at 20%, but lower than uterine cancer at 81% (National Cancer Institute of Canada 1995).

Table I shows the estimates of new cases and deaths for 1995 in Canada by age. A large number of women are diagnosed with breast cancer each year, and a large number of women die from breast cancer each year. Breast cancer is most common among women who are over the age of 50.
Table I - Estimated New Cases and Deaths for Breast Cancer by Age in Canada in 1995

<table>
<thead>
<tr>
<th>Age Group</th>
<th>New Cases</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 19</td>
<td>less than 5</td>
<td>less than 5</td>
</tr>
<tr>
<td>20 - 29</td>
<td>90</td>
<td>15</td>
</tr>
<tr>
<td>30 - 39</td>
<td>940</td>
<td>210</td>
</tr>
<tr>
<td>40 - 49</td>
<td>3100</td>
<td>580</td>
</tr>
<tr>
<td>50 - 59</td>
<td>3200</td>
<td>850</td>
</tr>
<tr>
<td>60 - 69</td>
<td>4200</td>
<td>1200</td>
</tr>
<tr>
<td>70 - 79</td>
<td>4100</td>
<td>1350</td>
</tr>
<tr>
<td>80 +</td>
<td>2100</td>
<td>1150</td>
</tr>
</tbody>
</table>

Source: National Cancer Institute of Canada 1995:40

Although breast cancer is the cause of death for many women, the five year survival rate is significant. Therefore, when researching women’s experience with breast cancer, it is important to recognize the potential for variation in experience due to age and length of time since diagnosis.

I was careful in selecting the statistics I would present in this thesis, because in doing the fieldwork I found that statistics are part of the cultural construction of breast cancer. For example, statistics are used to state how serious an illness breast cancer is. This is usually followed by a plea for donations to further research or some other good cause. This is an example of quantification rhetoric, where quantifying...
comparisons heighten the contrast of, in this case breast cancer, to other problems (Potter et al 1991).

One statistic commonly used is that one in nine women will get breast cancer in their lifetime, which is frightening. However, this statistic does not account for the changing risk over a lifetime. Older women are at higher risk of getting breast cancer than younger women, so the risk for a young woman is much lower than one in nine.

A second example of a statistic that is part of the cultural construction of breast cancer is the claim that breast cancer is the number one killer of women between the ages of 35 and 50, again frightening. However, there are few causes of death for women in this age range. It is still the older women, those over 50, who bear the brunt of the disease (see Table I). Portraying the disease as being of concern to women in the prime of life, rather than older women, is a good strategy for raising awareness and funds.

Individual women incorporated statistics into their stories, or in one case had statistics quoted to them\textsuperscript{27}, to explain their situations or to raise questions about the future. Commonly used statistics are the size of the tumour itself, and that after five years without recurrence the breast cancer is considered to have gone. The numerical representation of breast cancer in the narratives is extremely interesting. It leads me to wonder just

\textsuperscript{27} Angela, who was 26 when diagnosed, was told many times how unusual it was for someone her age to have breast cancer, comments she found frustrating. This case will be discussed in further detail later.
how our statistical representation of disease contributes to its cultural construction.

B. Staging of Breast Cancer Tumours

During the interviews many of the participants indicated what "stage" their tumour was. Staging of tumours is done by pathologists and oncologists to estimate the progress of the disease, its seriousness and the chances of survival. The estimates are all approximations and each case will be different (Olivotto, Gelmon and Kuusk 1995). However, the participants used the staging of their disease in their stories as an indication of its seriousness. The information presented here is from Olivotto, Gelmon and Kuusk (1995), and Olivotto (personal communication)

Stage I

Tumour is less than two centimeters, no metastases and no cancer in the lymph nodes. Treatment is usually local, including mastectomy or lumpectomy and radiation. Average five-year survival is 80% to 90%.

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There is a second staging system called the TNM. This system uses: 1) Tumour size and spread (T), 2) lymph node involvement (N), and 3) the presence or absence of metastases (M) (Olivotto et al, 1995). None of the participants mentioned this staging system in the interviews so I will not review it in detail.
Stage II

Tumour is two-five centimeters, but not involving skin or chest wall. Some lymph nodes may be involved, but they are moveable. No metastases. Treatment is again usually local, including mastectomy or lumpectomy and radiation, but also includes adjuvant therapy such as chemotherapy and hormonal therapy. Average five year survival is 50% to 70%.

Stage III

Tumour is local but advanced, and either it is fixed to the skin or chest wall, or the lymph nodes involved are "attached" to structures in the axilla. No metastases past the clavicle. Treatment includes high-dose chemotherapy, radiation therapy and hormonal therapy prior to surgery, if surgery is an option. Average five-year survival is 30% to 60%.

Stage IV

Cancer has spread beyond the breast and axilla to lymph nodes above the clavicle or to distant organs. Treatment is palliative care to improve quality of life. Average five-year survival 5% to 20%.

The staging system provides a simple construction of breast cancer. First, the larger the tumour and the further the spread, the worse the disease. Second, the greater the spread, the more aggressive the treatment (until stage IV) and the lower the

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29 Clavicle is the collarbone.
chances of survival.

In their stories, the participants linked the size and spread of the tumours and their type of treatment to survival. They incorporated this into their construction of cancer as a way of evaluating the seriousness of their particular cancer.

C. Health Services Available to Women Who Have Had a Diagnosis of Breast Cancer

Two main factors which contribute to the participants’ experiences and which may be different in British Columbia than in other jurisdictions. The first is the availability of a provincial health insurance system. The second is the centralized delivery of treatment for cancer. These two factors contribute to the development of an institutional culture to which all the participants were exposed during their diagnosis and treatment. As a result, the sub-narratives dealing with the period of diagnosis and treatment have little variation. This will be described in Chapter VI.

National health insurance is available throughout all of Canada, but the insurance plans are administered and subsidized by the provincial governments\(^{30}\). In British Columbia the insurance plan is called the Medical Services Plan (MSP). MSP is available to all residents of the province for $36 per month once residency in the province has been established. Many employers pay part of or all of this fee as part of an employment contract.

\(^{30}\) The core services covered by the provincial insurance plans are mandated by the federal government under the Canada Health Act, with some minor variations.
Otherwise, each individual is responsible for registering in and paying for MSP. Those people on social assistance are often covered as part of that assistance. While there is the possibility of someone not being covered by MSP, this can usually be dealt with by having the individual pay the fees after the fact.

MSP covers the cost of all physician visits, treatment and laboratory services, and hospital costs. Some services, such as physiotherapy, have limited coverage and require a small "user fee". Therefore, for a woman in the province who is covered by MSP, the financial burden of being diagnosed with breast cancer is related more to lost wages rather than to medical expenses. The impact of medical costs on the experience is very different from that in the United States, where the concern about treatment cost is a major part of the experience.

The British Columbia Cancer Agency is a treatment, research and teaching facility. It is a health care facility independent of any other hospital in the province. All women who live in mainland British Columbia\textsuperscript{31} and who require radiation treatment are given that treatment at the Vancouver Clinic of the British Columbia Cancer Agency. Many such women who do not require radiation are still referred to the Vancouver Clinic for assessment and consultation.

\textsuperscript{31} The mainland of the province is all of British Columbia except for Vancouver Island. Therefore some people have to travel a long way for treatment. Currently the British Columbia Cancer Agency is in the process of opening up treatment facilities in the interior of the province to deal with this problem.
Other patient services are also available at the British Columbia Cancer Agency, including access to its library and patient counselling and support services. There are two formal support groups for women who have had a diagnosis of breast cancer, one for those going through treatment, and one for those who have completed treatment. Some of the participants used these support services.

The existence of a centralized treatment facility and the fact that sampling for this study was done through this facility creates a similarity of experience that would not be as common elsewhere.

I have provided only minimal information about the health services available to women who have had a diagnosis of breast cancer. However, in the long narratives in Chapter V, the impact of provincial health insurance and a centralized treatment facility on the experience becomes evident.
Chapter V - Narratives of Living With Having Had a Diagnosis of Breast Cancer

Illness narratives are represented in the accounts of individual experiences with illness. To ground the reader in the experiences of the participant I am presenting two in-depth case studies. Each is an individual’s account, and is unique in many respects. However both have a common structure. Both also have aspects that are shared with other participant’s stories.

Like the majority of the participants, the tellers of both these accounts start their stories by telling how their cancer was detected, diagnosed and treated.

The remainder of the story is an account of the impact the cancer has had on their lives and the lives of others. This section of the story is their way of making the cancer meaningful through the rewriting of their personal biography to account for and accommodate the cancer.

Each participant does this differently. Both talk about the future and try to draw their cancer story to a conclusion. It is the uncertainty of the future, the possibility of recurrence, that makes this very difficult.

Through the construction of their personal accounts the participants invoke a variety of breast cancer narratives. These narratives influence the presentation of structure of the story.

32 The case studies have been edited to cover material of interest for this thesis. They contain both paraphrasing and direct quotes. The quotes have been edited to make them readable. For this thesis I am more interested in the content of the material than in a linguistic analysis.
As well they provide a basis for the selection of content to present in the account.

A. Anne

At the beginning of the story of her diagnosis and treatment Anne describes how the diagnosis disrupted her life. She goes on to describe how she reconstructed her sense of identity and body through separating the cancer from herself and describing her treatments as successful. She also describes in great detail the change in her construction of biographical time as she went through treatment and the post-treatment period.

As Anne talks about the cancer in her life she develops an account of what may have caused her cancer, a personal risk profile. She also talks at length about the impact the cancer has had on her life, and how it has provided her with an opportunity to reevaluate her life and make changes.

Anne’s cancer story is, in a sense, incomplete. She talks about the future and the role, she hopes a minimal role, the cancer will play. However, throughout the narrative leading up to this point she describes many challenges to her developing understanding of breast cancer, such as having to deal with the fear of recurrence at the end of her treatment and her family’s reactions to her cancer diagnosis. She articulately describes the ambiguity of breast cancer.

Anne is a 35 year old professional. She is a health professional and is articulate in the use of medical terminology. She had been diagnosed with breast cancer about eight months
before the first interview. She participated in four interviews in April, May, June and August 1994. All the interviews were done at her kitchen table, although in two different apartments. The first and second interviews were done in an apartment that she was sharing with a friend, the last two in her own.

Anne is very thoughtful. She speaks slowly and precisely, and chooses her words carefully. After listening to copies of the audio-tapes of the interviews she was pleasantly surprised at how articulate she was. However, she also found the interviews to be very intense and tiring. She compared them to the intensity of discussions in support groups for women with breast cancer. She said that in both situations you chose your words very carefully.

The first interview took place at the end of April. The interview started with my asking Anne when she was diagnosed and what happened.

She recalled it had been in the late summer of the previous year. She had been down at the beach in the evening. Later that night she woke up uncomfortable, with a stinging in her back. She was a little concerned, thinking that she might have a bad reaction to an insect bite. The next morning as she was doing Breast Self Examination\(^{33}\) she discovered a lump in her breast.

"I found it myself. And I knew at that time that, it was different, that it was probably cancer. Just from feeling the lump, and I hadn’t felt it before, and I’ve always had lumps and bumps in my breasts. But this was different. It felt different. And I still

\(^{33}\) Breast Self Examination (BSE) is a manual self-examination of breast tissue used to detect changes in breast tissue. The Canadian Cancer Society recommends women do BSE once a month (Canadian Cancer Society 1991).
wonder how I could have missed it because it was 1.7 centimeters . . . A little voice inside of me said, 'Get this checked out, this is not right'."

Anne phoned her family doctor immediately and made an appointment for the following week. At that appointment she discussed the situation with her doctor and decided that she wanted to be referred directly to a surgeon rather than having any tests done first. She appreciated her family doctor giving her that option.

In two or three weeks she had seen the surgeon and had a mammogram34, a needle biopsy35 and an ultrasound36. After all the tests had been done she came home from work to find a message on her answering machine asking her to call the doctor's office.

"I just knew. It was just a feeling I had. It turned out that there was [malignant] cells in the needle biopsy they had taken. So that's when things really started to happen, . . . Maybe a part of that was fear. Anticipation of the worst. But something inside of me I think was preparing myself for some bad news, you know. It's almost like that same little voice, when I had the choice between a mastectomy37 or

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34 A mammogram is an x-ray of the breast tissue. It is used for both the diagnosis of breast lumps and screening for breast cancer (Canadian Cancer Society 1991).

35 In a needle biopsy a surgeon inserts a needle into a lump to get a sample of the tissue. There are two types of needle biopsy: fine needle that only takes a few cells, and a larger-needle that takes a small piece of the lump (Love 1990).

36 An ultrasound is a test where high-frequency sound waves are sent in pulses through the breast tissue. It is used to determine if the lump in the breast is fluid-filled, such as a cyst, or solid, such as a fibroadenoma or a cancerous lump (Love 1990).

37 A mastectomy is the surgical removal of the all the breast tissue. A modified radical mastectomy includes the removal of some of the lymph nodes from under the arm on the same side as the affected breast as well. A radical mastectomy is where the breast tissue, the lymph nodes and the muscles of the chest wall are surgically removed. A prophylactic mastectomy is a
a lumpectomy that little voice said, 'Go with mastectomy.' That was not a hard decision on my part either. There was something within me telling me these things."

Anne took her best friend with her to her second appointment with the surgeon for moral support and also to take notes, because Anne knew she would not remember a lot of what the surgeon was going to tell her.

After the second appointment Anne went through further testing to see if there had been any "mets".

"And that was a difficult period. Waiting for the results of that. Because depending on those, the results of the tests, it would affect the surgery. But they all turned out negative, thank God for that. They booked me for surgery towards the end of September... It was fortunate that I was bumped in a week earlier too. Alleviated a lot of the mental anguish I was going through too... The waiting period is just terrible. You have so many questions and no answers. Or so few answers... I must say the doctors were wonderful. The whole thing was hastened along. In comparison to some of the stories I have heard where women have had to wait for longer periods of time either to get into see a doctor or to have the surgery. I can't imagine even what that would have been like to wait longer than what I had to wait. And my process was very fast. A month and a half."

I asked Anne to talk about making the decision to have a mastectomy rather than a lumpectomy.

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mastectomy done on asymptomatic women to prevent breast cancer (Love 1990). In these interviews a "mastectomy" usually refers to a modified radical mastectomy.

38 A lumpectomy is the surgical removal of the lump with a small rim of normal tissue around it (Love 1990).

39 "Mets" is short for "metastasis" the spread of cancer to another organ in the body. The spread is usually through the blood stream. Breast cancer most commonly spreads to the lungs, liver and bones (Love 1990).
"To me perhaps it was propelled by fear somewhat, you know, what about the remaining tissue? What if they don’t get it all? ... I guess there was a little bit of anger in there and I thought, you know, this breast has betrayed me, it has threatened my life. I’ll get rid of it. Because I don’t want to have to worry about reoccurrence in the affected breast as well as my healthy breast. Now I only have to worry about one breast. ... I’ve never been a breast person. It never meant that, it’s never played that great importance in my life. ... I thought, this would be a means of maybe sustaining my life, of helping me get over this disease would be to just take the breast. And that little voice that I was telling you about said, 'Go with the mastectomy, that’s the thing to do.' Yeah, so I had the mastectomy and the axillary node dissection as well. And, ah, they took out 27 nodes and one was positive for cancer. So, that indicated then that I’d have to get into further treatment like chemo. So I did that too."

Anne spoke briefly about her experience in the hospital for her surgery. She talked about how even though she worked in a hospital she was not aware of what came after the surgery.

"Having the drain in and it’s painful to have the drain taken out. And umm, you know, the incision’s all covered up and that first unveiling of the scar, you know. Your arm is, my arm was - I could hardly get my arm up at all because of the manipulation in my underarm to get at the lymph nodes ... so that took physio. So these things were things that I’d never thought of."

Anne came home from the hospital at the beginning of October and had her first appointment at the British Columbia Cancer

40 The axillary lymph nodes are the lymph nodes in the armpit. In an axillary lymph node dissection the lymph nodes are surgically removed and examined under the microscope. If cancer cells are found in the lymph nodes it is an indication of microscopic spread of the cancer (Love 1990).

41 "Chemo" means chemotherapy, the cytotoxic drugs given for cancer treatment (Love 1990).

42 After surgery a drain is placed under the skin in order to drain the fluid away from the area were the breast was (Love 1990). Drains are left in for a few days.
Agency a few of weeks later. She remembers the exact date she had her first chemotherapy treatment, which was less than one month from the date of her surgery. I asked about her first appointment at the British Columbia Cancer Agency.

"Well, I took my secretary with me, my friend (laughs). And you know I walked in the doors, and I just broke down, I turned around and walked out. And I just stood on street and cried my eyes out. You know it was such a reality by that point. Just a reinforcement that this is happening. Now I am here to discuss treatment. So I composed myself. And, the first person I came in touch with was the receptionist, and I guess she'd seen it all before, cause she was there with a box of kleenex. And she was wonderful."

At this first visit Anne talked to a nurse who took her case history, and to a social worker. She also meet her oncologist for the first time, and discussed her case with her. They discussed the type of cancer she had. She was told the various statistics about survival rates. Anne felt it really wasn't necessary to talk about all the statistics. She was told about the chemotherapy she was going to have, how long it would last and the possible side effects. She was also told what tests would be done before each chemotherapy treatment and how she would be monitored. When she was finished that appointment she felt pleased, confident, and comfortable - "as comfortable as I could feel knowing what I was going into."

I asked Anne about the chemotherapy.

"But when I think back, you know, I don't like to say something's been really shitty or this is a nightmare. I try to keep positive about things. But I have to say it was gross, it was a gross experience. . . The chemo I felt, I just felt like my whole body had been puffed up or something from it. I felt swollen when I came out of there. And I felt kinda hazy and sluggish. . . It would take probably four to six hours in total. The chemo administration itself is a shorter period of time maybe an hour, hour and a half. But by
the time you go in there and have your blood work done, they have to wait for the results, see your oncologist, then up for your appointment, you know. I’d be there for four to six hours so that’s a long stressful day.

And you know you feel pretty rough when you come home. This same friend of mine came to my treatments with me. And then she’d come back and I had my own place at the time, she’d cook dinner. Friends like that, I mean it’s wonderful when you have friends like that.

On the 15th day my hair started falling out. They said it would happen and it did. I just ran my hand through my hair, and there it was, you know it was coming out. And I just felt so betrayed when that happened. Now my hair is falling out. I’ve lost my breast, my life has been jeopardized to some degree, now my hair is falling out. What else is going to happen, . . .

So I went down to the little shop and I got them to cut it off. Eventually to make a long story short, I had this friend or mine over and I said well I’m not gonna be picking this stuff up until it’s all out I decided to shave my head. So I thought we’ll make a party of it. I sent her out, and get a can of shaving cream and a six pack of Bic razors and we’ll do it. And we did, it was great. I don’t know I guess, you’ve got to look at things from a silly point of view. That’s the only way I could get through it was to be silly about it. You know have a laugh. If I’m going to go bald I might as well enjoy it. . . I decided not to go with the wig. That’s not my style. . .

When your eyebrows start falling out and eyelashes start coming out, I found that hard. Your face looks, there’s no definition to your face really without your eyebrows or without your eyelashes. . . It’s such an altered body image, you know. You’ve gone through a total shocking experience. There’s been a total lose of control of your life, and now these things are happening to your body that you can’t control. . .

I called myself E.T. because I looked so weird. But we laughed about it anyway I mean what’re you going to do? No point of sitting at home. I mean if you’re gonna fight for your life, if your gonna live, you have to live your life for life and not for death. . . Fear, fear is a big one. You wonder if they are going to ‘get it all’. If there are any of those stray cells floating around somewhere."

I asked Anne how she felt when she had finished her
chemotherapy. She was really looking forward to being finished and trying to get some "normalcy" back in her life. However the month that she finished her chemotherapy she got pneumonia. She got the pneumonia because her immunity was low after going through the chemotherapy. Being sick gave her quite a scare because she thought the cancer had spread. "It was devastating."

She had a low grade fever and trouble sleeping. She was given antibiotics and had to wait for six weeks to see if her lungs cleared. So again there was a waiting period. A part of her had been looking forward to being finished the chemo, then this happened, so there was a delayed reaction.

"The other side of the coin I find was that, umm, you are no longer in that situation where there’s all the doctors and nurses and you are going there every 21 days, and you are actively doing something, to fight this, you know, in terms of treatment. So after the chemo it’s like, shouldn’t I be doing something? What do I do now... There is a joyful anticipation for it to be over and then when it happens it’s, it’s rather frightening. It is like you have to come out from under the wing now."

Now Anne has been doing investigations on her own about what she calls complimentary therapies, therapies to compliment the medical therapy she has had. Complimentary therapies include herbal medicines and vitamins. She has found that there is a lot of information available. All you have to do is go to a health food store to see all the different products. In her experience there are many discrepancies in the information available, as different people recommend different things. She is doing her own research. She goes to the stores and gets literature and telephone numbers. She says it’s like there is an underground
subculture. She has made no decisions, but is willing to look at anything.

During our discussion Anne mentioned changes that had happened in the last couple of years. I asked her to tell me more about those changes. She said a lot had happened in the two years prior to her being diagnosed with breast cancer. A relationship she’d been involved in for six years had broken up. She had had a drinking problem and had been sober for 13 months prior to her diagnosis. Also, she felt that she had been going through radical changes in her attitudes and in her view of life.

"What I had thought maybe was so important before, and what I would waste a lot of my own energy on, I won’t do it any more. I won’t place, I don’t place great importance on, a lot of society’s standards now. You know, in terms of the way you dress. Things like that . . .

One of the main things that has come out of it is that I am going to live my life for myself now. And I am not living it for anybody else. And I know there is rules and regulations in life and in society, . . but, you know, I, I’m going to follow my own heart. . . Just that I’m trying to find my inner self. It has given me ‘cause to examine myself. . .

I think I had put my life on, on hold, for so long. But I was living a good life I don’t want to make it sound like I was sitting here waiting for cancer to happen or something. I mean I was having a good life but, . . when I look back I was off track. And maybe, you know, if this had never happened, maybe I would still be at that point, . . But I think maybe the cancer has been, a catalyst to do that, now’s the time to do it. . . It is almost like it has given me reason and freedom in my own mind to say, ‘Okay this is what I am going to do.’ I am not going to wait and umm, logically plan everything out because life doesn’t work that way. . . It has allowed me to let go of some things. It has given me a freedom in some way."

Part of this process of change is that she started to develop a faith. Her faith was growing through readings and
things that were happening to her, "through help that I had felt
I had received from God." When she was diagnosed with cancer she
was thankful that she had started to develop her faith.

"It’s carried me through a lot of the really dark
times. And it’s given me a sense of joy, that I’ve
never felt before. Now whether, that must be from the
relationship that I’ve, the personal relationship that
I think that I’ve established with God. He’s proven
himself to me. And so out of this big nightmare you
know, I, I can truly feel this, this, comfortable
wonderful warm sense of happiness, and joy and
contentment. So maybe it’s, it’s that comfortableness
that has given me the initiative to get on with certain
aspects of my life that I hadn’t before."

Anne mentioned that she was planning a trip to see her
family. Friends she has known for a couple of years say that she
has changed a lot. She wonders what her family will see when she
goes back. She is unsure about going back to see them.

"I want to be strong enough within myself.
Because when you go through something like this, . you
know, the growth and the changes can’t help but remould
you, and reshape you entirely. So it is kinda like I
don’t want to go back and, be all over the board I
wanna be together. Represent myself to these people
again."

Her family has not been around during her cancer experience
as they live in another part of the country. However, her mother
did come out when she had her surgery.

"I had a lot of anger. And, I had a lot of issues
to deal with. You know, my breast was gone. I’m mad.
I’m in pain. And I couldn’t stand, to see the pain on
her face, you know. She was a wreck, and that was
just, that was gonna eat me alive, seeing that. So, I
got my secretary, (laughs) I got my secretary to ah, to
talk to my mum. And I told my mum to go home. I sent
her home. That was so hard. . . I didn’t want to hurt
her, and add to the pain she was in because she says, I
mean, its like I am sure any mother would say, ‘It
should be me and not you.’ And she said that to me."
She has not seen her mother since then, but she does call and talk to her parents every week.

When she was first diagnosed she could not tell her family about her cancer, so she got her secretary to do it.

"I couldn’t, I couldn’t say that to them because I knew that it was going to just tear them apart. I knew that the pain that they were going to go through when they heard that news. I couldn’t bring myself to do that...

I waited before, you know I had a desperate need to tell them what was going on, and my family and my friends but I didn’t want to say anything until I had some answers. I thought why should I put this on them because they’re gonna have the same questions I have and I don’t have any answers.

So I waited before I told anybody until I knew that okay we were going to go have the surgery and I had the booked date for surgery. Then we made the phone calls... That was one of the first things that I thought of when I was told how do I, how do I tell my family. My mum and my dad. I knew it was gonna just... umm ah, I wouldn’t wish it on anybody."

After getting to know Anne I asked her what she thinks caused her cancer. She mentioned that she has read Bernie Seigel’s books and believes what he has written.

"You know, I can look at it from the point of view of umm, just draw of the cards. Part of me looks at it that way. Umm, you know instead of saying why me? Why not me? That sort of thing.

Another part of me says, that I almost, you know, it is hard to say things like this because I am not sure if I totally believe it or not, but it’s like it was, it’s been a gift to redirect my life. I was going in the wrong direction, so this, this is the stop along the road that says maybe evaluate what is going on in your life and make some changes. And those changes are maybe things that I have wanted to do for a number of years but just haven’t had the nerve or the guts to do it... That’s umm, not a medical definition of why I have it but I think there’s gotta be something there other than just getting cancer..."
If I could have avoided this disease but still gained, the insight and everything that I have been filled up with since my diagnosis, I mean that would be great. But unfortunately or fortunately whatever way you wanna look at it, you know, you’ve got this disease now, and, who knows, we’ll see. But ah, I mean my, my intent is to be around for awhile, quite awhile you know.

I plan on living a good life. And, ah, and it’s almost like I am going to live the life I was born to live now. Maybe not let a lot of, judgements or other people’s ideas or establishment’s ideas dictate what I’m going to do now with my life. So it’s been a gift in some respects. What I have gained from the experiences. It is almost like its outweighed the disease."

Anne described the experience of going through changes as being like a pendulum that is slowing. You go through the extremes and then find common ground in the middle somewhere. Some days are very difficult still.

"Sometimes I get up in the morning, and I still can’t believe what’s happened. Occasionally when I’m getting dried off in the shower I’ll catch a glimpse of myself, in the mirror. Now I can look at my scar, and, I think I’m relatively comfortable with that, but occasionally it just kinda catches you. Wow, yeah I am missing that, that part now.

And then some days are worse than others too, you know. I still have bad days. Down days. But I think what I find is you have, allow yourself that time, but don’t dwell on it. There’s no point in stifling the emotions, so it is just going to eat you up alive.

And, you know, as I say to a friend of mine well if something’s not right or something needs changing, or I’ve got some bad news or whatever deal with it allow myself the emotions but, you know I’m not going to grow a tumour over it. Each day is going to be here it is what you’re going to make of it."

Anne does think about the cancer, that it may recur and that it might kill her. Sometimes she finds it hard to sit in the support group and listen to other women talk about their
reoccurrences, or to hear that someone has died.

"It is always in your face. The issue of mortality. And I know that we are all going to die, it’s inevitable. But the idea is that you have, you know a good life, and you get old and die. Not that you are 34 or 40 years old and you know you spent the last two or three years in treatments and it’s back . . . Yeah that’s hard. I don’t like thinking about it, but it’s a reality.

But I think you have to keep things in their place too. You know, that’s where hope comes in and positive emotions and positive attitude. Because even if it does come back I don’t want my time to have been wasted in the interim. Being negative or unhappy not doing what I want, not working toward the goals that I have. But yeah, that’s a raw reality that we all face."

Knowing that the cancer may recur and be the cause of her death makes it difficult to talk to other people about what has happened.

"And it’s a painful reality too . . . a few people have said to me, 'Did they get it all?' Well I don’t know, and neither do the doctors. Nobody knows. That’s why I’ve had the chemo, that’s why I’m on the tamoxifen 44. That’s why there is that doubt . . . I’ve learned to accept that in people because you know people don’t understand the process of cancer and treatment. But my blood would just boil when people would say that to me . . . and I guess it would anger me because I have to say I don’t know. There’s no concrete answer I’m doing all I can with what I have, but nobody knows . . .

I think because a piece has been removed. The diseased piece has been removed. But I guess people don’t realize that’s there’s the stray cells that break off that’s why it was in my lymph node. Now who knows where else it went. I’ve got a good bill of health right now and I feel, I feel quite comfortable that I’m okay. But there’s always that doubt. If you could just get rid of that doubt. But you can’t so you learn to live with it."

That doubt is why it is good to go to the support groups and

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44 Tamoxifen is a drug, an estrogen blocker used in the treatment of breast cancer. It is usually taken for three to five years after diagnosis (Love 1990).
talk to other people about it. Anne first started attending a support group right before she had her first chemotherapy treatment. She is still going.

"Unless you've had it you can not fully understand what it does to your life. In a support group the women have all experienced it. So there's a lot of emotional support to be given, and taken. Umm, a lot of advice on how to deal with maybe some emotions that you're having or problems that you're up against. . . . What to access to get information. I think that that's important. There's a closeness there. Must be like AA\(^{45}\) or something like that, there's a common thing that holds you together."

I asked Anne whether she considered having reconstructive surgery\(^{46}\). She has not, it is not a priority with her. She is not "seeing" anyone, but in the future that may change and then she may want it.

"My attitude about it right now, that if I was to do it I wouldn't do it for somebody else I'd do it for myself, you know. If my partner couldn't handle it, the scar or the, the breast missing then that's something that he would have to work at. Not me. Exactly, I'm there, I'm understanding I, I can lend a good ear type of thing and we can talk about the issue but I wouldn't do it for somebody else. 'cause it's my body."

The second interview was three weeks after the first, which provided both Anne and me the opportunity to reflect on what we had talked about. As we got started I asked Anne to talk more about her life before she was diagnosed with cancer.

"And it was quite an adjustment to be living alone again. You know trying to get out and meet new people, and develop new friendships, and things like this. . . . That's where my life was prior to this happening. I put it in terms of . . . it was like after a number of

\(^{45}\) AA refers to Alcoholics Anonymous.

\(^{46}\) Reconstructive surgery is where a plastic surgeon will reconstruct the removed breast, using either an artificial implant or the woman's own body (Love 1990).
years of trials and not being very happy with what I was doing and where I was going and who I was. I'd made some changes and I was getting it together. It felt good. And, you know, it wasn't too long after that, that umm the cancer became evident. So I have to, I think and I say that if it was going to happen it couldn't have happened at a better time because at least I think that I was in a mental state where I could cope with this now. If it had happened a year or two before I would have had a lot more problems to deal with besides just the cancer."

Then I asked Anne to talk about her life since she had finished her cancer treatment and recovered from pneumonia.

"It was then at that point that you really start to think of your recovery now. And I must say that this recovery period has been, just as difficult as going through the treatment, I have found. But in a different way. It's like all of a sudden you're removed from that focus, when you are in treatment you can focus on what you're doing because you have appointments and every 21 days you have chemo, umm, you're going to the support group, you're meeting a lot of people. I actually equate that portion of it to the fight or flight response. You've been hit with something and you go into this fight, I go into the flight response... You're up. You're ready. You're ready for bad news, as much as you can be, umm.

But after that, then you're told, 'Well okay, we'll see you in three months.' And there's no, I have found it difficult and, as I thought the other day, it's like there's no bridge from the treatment at the Agency in dealing with that focus to when you're told, 'Okay, it's all done,' umm, and, as somebody said to me, 'Now all we do is pray.' Well there must be something else I can do too, I mean. You just put all this into my body and here I am with no hair and blah, blah, blah. And now it's like okay well, we've done our part and that's not to criticize the Agency that's what they're there for and my experience has been so good with them, I've been treated so well.

But, now it's up to me, to get out there and go to different stores talk to different people who aren't on a register to contact after treatment in terms of what you can do for your health or is there any complimentary therapies maybe you can go into."

47 The Agency refers to the British Columbia Cancer Agency.
A couple of weeks before this interview Anne had celebrated her birthday. She talked about some of the feelings that event had triggered.

"But that was really interesting, you know, a birthday has never bothered me in terms of age and I don’t think of things really in terms of age. But for some reason, and I don’t know what the reasons are, this - this birthday was different. Because I think it made me realize that umm, maybe some of my hopes and dreams won’t come true in terms of having a family because I’m 35 and I’m on the tamoxifen..."

The question of mortality, came up, you know. Maybe I won’t, you know, get to be an old lady and fracture my hip, and all those things that happen to older people maybe that won’t happen to me. I just found it hard. But then I thought there’s no guarantee anyway, somebody said to me. But I think the difference is there’s even less of a guarantee now. That’s why we have to make the most of each day... So that was umm, so that was an interesting day."

Anne feels that she has changed during her experience with breast cancer.

"I seem to be less tolerant of some things now and more tolerant of other things. Which is interesting because I used to be generally a very patient person on all levels, but now I find that for the most part I don’t like to umm, I don’t want to call it waste my time, but I don’t want to spend a lot of my time doing things, that don’t mean that much to me... I want, I like to be productive with my time.

But I can still just be silly too. You know I allow myself that. I’m not saying that I have to be totally serious all the time and never have any fun.

But there are things that I just I don’t particularly enjoy doing, that much. And I won’t do it now. I guess that’s the difference before I would kinda go along with it and, tolerate behaviours in people or, idle conversation. And I will get up and leave now. Bow out gracefully now and say I’m gonna go home and read or whatever..."

48 As tamoxifen is a hormone it is not recommended that women become pregnant while on the drug (Olivotto, Gelmon and Kuusk 1995). Anne has also had chemotherapy which in some cases can bring on premature menopause.
We’ve got, we’ve been given a life, and, we should use our minds you know and, and love one another and try to build good things, for the kids that are coming up, and, I guess a positiveness. So I don’t wanna be, so I don’t want to be around to much negativity, you know, bitching and complaining and this sort of thing."

At the end of February, at the end of her chemotherapy, Anne had moved in with a friend. In part it was to help Anne out financially, until she knew where she would be going in the future. Anne enjoyed having a roommate and two cats, but considered this an interim arrangement and planned to move soon.

"I want to, I wanna get on with my life. Umm, this being, this living arrangement, is like the tail end of maybe stage II. Because it’s still related to the cancer, that’s why I’m here okay. I’m anxious to get out and get my own place again. . .

The last couple of months have been somewhat hard - it’s a bit difficult. I’ve been angry a lot, been frustrated. . . But it’s like the last you know three or four months like all of a sudden there’s been the ugly bag’s been brought out and you have the frustration and the anger and the fear and the doubts. So, there’s that kinda like black cloud in this little ugly bag and you open it up and then you have a look at it. So that’s dealing with all the negative things. That’s what I’m working through right now. And again I feel that it won’t be too too much longer before I can you know settle a lot of those emotions in my heart and in my mind. . .

This is why I like the support group. You go there and you can verbalize this to other people, and they’ll say well you know maybe your hormones are a bit out of whack right now, or maybe it’s the drug that you’re on doing this to you. And that’s, like yeah, maybe it’s not all me, maybe there is some outside influence in this too and that’s good, it kinda takes the heat off myself a little bit too. . . understanding that there are other factors as well. And even what is going on in your personal life too has bearing on how you’re feeling in terms of the disease process and what you’ve been through. . . Everything has a bearing on how you’re feeling but I just think that it’s important that you recognize your feelings and you deal with them."
I asked Anne to talk about her friends’ reactions to her diagnosis of cancer. She said that there had been a variety of responses. Some friends have been in touch, always inquiring about how she is doing, but it is not the focus of what they talk about. Another she has not heard from much at all.

"It’s funny because one of the questions I’m frequently asked is, ‘Well did they get it all?’ ... I don’t know, I think they did. Another person I know’s reaction to it is, ‘Well don’t worry it’s just a little thing’ ... Perhaps this person couldn’t deal with it and that’s their way of saying, you know. I think deep down maybe they’re terrified for me. ..."

Not understanding I think is one of the problems and total lack of knowledge about what it is about. ... They don’t understand it. They think that you can, have a lump or a breast removed and that’s it. They don’t understand why you have chemo, or radiation, umm. That, that there’s no guarantee that quote unquote they got it all. ..."

It’s an abstract disease. ... That’s what it is. There’s not really a lot of answers. There’s a lot of statistics and studies, but really when you filter it all down we still don’t know too much. So, with all the things that can go on in terms of surgery, follow ups, what you know, side road and problems that come up like pneumonia or you know radiation if it burns your oesophagus. These sorts of problems you know.

What started out as one word, cancer, is by the time you try to get the full picture it’s totally abstract it reminds me of something maybe Picasso would have done. Where you look at it and oh yeah I can see that and I can see that and you put is all together and it makes sense but it doesn’t. ...

For many people cancer is a powerful word. That word triggers many different responses based on their experience with cancer.

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49 Radiation therapy is used in the treatment of breast cancer. Radiation is commonly used in conjunction with a lumpectomy to destroy cancer cells that may still be present in the breast (Love 1990).
"It's like I can walk down the street and meet somebody and tell them what's happened and they'll say, 'Oh my aunt had that she's fine. She's ninety years old now. Fine. You'll be fine.' The next person you tell it too, 'Gee, my aunt died of that.' So you go from one extreme to the other you know. And you're kind of slotted somewhere in the middle."

We talked about Anne's work. She explained that she worked right up to the Friday before she was to have her surgery. In order to be able to get the tests done before the surgery Anne just took overtime days. "I didn't tell anybody at that time because I didn't have any answers. The same reason why I didn't call my family until I had some answers."

Her friends at work were "just great". The week after Anne came out of the hospital she got phone calls, cards and flowers. "They've been super." Even now she pops into her work site occasionally to see her co-workers.

Just a few weeks ago Anne saw a video on women's experience with breast cancer\(^{50}\).

"You know it had been awhile since I had watched something like that and it just, surfaced my emotions. I felt really emotional. Teary just listening to these women. Because it's just like you can totally relate to what they are saying, and you can feel what they are feeling. So the emotions were very easily brought up again. And I find it just - I find that's one of the changes that's occurred in me too. I can be, I can become, I can relate on a very emotional level very quickly with people that are in pain. I could before, I was always, you know, sensitive to that sort of thing, but this is more like an experience with people than just, you know, listening to somebody's story... Feel what they feel. That surprised me. It took me a little bit off guard when that happened that day. That I would get so emotional just watching that video and listening to these women talk. It hit so close to home."

\(^{50}\) Destined to Live: The Roads to Recovery, (Landsbury Company 1988)
A couple of months ago Anne went out and bought a prothesis\textsuperscript{51}.

"I'd just been wearing that little fibre filled ball that they give you and it tends to migrate, you know. So I went out and got a prothesis, and it's really made me feel better wearing it. It gives me a bit of weight on that side. And much better shape than the ball did. I call it my Betty. I don't know why, Betty, Betty Boob. . . Because I hadn't planned on doing that, buying that, that particular day. I'd been thinking about it but I hadn't made any decision to do it. And one day I was out with a friend and, that was it. Let's go check out a store and, and I bought one. Kinda interesting how time, so much is timing and when you're ready for it and then you do it. I think that's what this experience is all about to. Is getting ready for something preparing yourself and then when you feel good about it, feel right, you do it."

Anne found the prothesis quite expensive. It cost $300. the bras to go with it are $40 each. She is glad her prothesis is partly covered by her extended health coverage, although the bras are not. However, for her the cost is worth it.

We talked about some of the fund raising and awareness raising that has been going on around breast cancer. Anne was very glad to see it happening and thinks it is very necessary. In the future she would like to become involved in volunteer work on something to do with breast cancer, although in exactly what she is not sure.

"I'd like to know more about what's out there in terms of a stronger stance perhaps that we could take, just for a stronger voice. You know, you mean, you look at AIDS, and how particularly you know I think initially it was the gay community that really was vocal in getting the knowledge out there and saying like there's something wrong here. And it's just a matter of, of coming together and getting enough voices and enough people and not being afraid to back down.

\textsuperscript{51} A prothesis is an artificial breast worn in the pocket of a specially designed bra.
But you see I don’t know a lot of the political issues at this point. I don’t know what their platforms are or what they’re saying these groups. Although you know there seems to be more, umm, more of an attempt to make it more visible. But I don’t know if that’s maybe just Hollywood in some, in some way putting out movies or this sort of thing, you know, because it’s maybe the in disease at this time. Every disease has it’s survivors and its victims, and its support groups, and people who are totally affected by it. I guess breast cancer is mine.

I asked Anne what she had meant in the first interview when she said that she didn’t feel it was important for her oncologist to tell her all the statistics.

"Well the problem for me I know is that I don’t want to be told a bunch of numbers. I don’t want to be told that you know x number out of, or x out of ten women survive with this treatment or with that treatment. I mean maybe it does reflect the truth of the matter but still, I guess there’s a part of me that I don’t want to know that.

I want to have my treatment. I wanna do what I can for myself. I wanna be well. And I don’t wanna hear your numbers because that might make me think, well, maybe I don’t have as much of a chance. Numbers make it nice and neat and this isn’t a nice neat disease. Nice neat numbers in an abstract disease. I don’t wanna hear it.

Maybe that’s a part of denial maybe, on my part right now but, I don’t need the numbers. But I think we should be concentrating on the positiveness you know. And not to candy coat the issue, but just to keep things on a positive note. On a more acceptable note to people.

You have to know the facts. You know everybody knows that cancer is a potentially fatal disease anyway, so must we go over and over about the numbers, and if you take tamoxifen it increases your chances by x percentage, and yet, on the same hand they’ll tell you in the same breath but you know evidence has proven that you can develop cancer of the uterus, or, G.I. problems, it might send you into some sort of mixed up hormone imbalance.

52 "G.I." means gastro-intestinal.
I can understand why they do it, but, I just sometimes, I mean maybe say it once and that's enough. . . When it comes to disease statistics are basically based on, I mean success and failure but, I think when I think of statistics I think of that they're more involved in death than in life. . . You can count on death."

The oncologist had talked about percentage of people who had survived with various treatments at five and ten years, but she couldn't remember exactly what she said.

"Now, the big thing is your five year check up. You know if you make it to five years and you're still clear, that's good. I mean I look forward to that 'cause I'll be 40, you know. That'll be a good year I'm sure. At this point I don't think too much about the numbers. . . There's enough to think about without worrying about the what if's."

The third interview was three weeks after the second. By this time Anne had moved into her own apartment. She was very happy in her new place. Again the interview took place at her kitchen table. I asked Anne if she knew the name of the cancer she had.

"It's adenocarcinoma of the breast. The tumour was estrogen receptor positive, 1.7 [centimeters]. Umm, I think it's a stage II because my lymph nodes were involved, there was one lymph node of 27. So it's a stage II. . . There are different types of breast cancer. That's what mine is. It's not an aggressive type of tumour growth. Some women I know have had more aggressive cancer, so the treatment was more aggressive. The treatment fits the tumour type of thing."

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53 An adenocarcinoma is cancer that arises in gland-forming tissue (Love 1990). Most of the other women interviewed did not mention the type of cancer they had.

54 Estrogen receptors are proteins found in some cells, to which estrogen molecules will attach. If a tumour is estrogen receptor positive it is sensitive to hormones (Love 1990).
That was all she could remember about her tumour. She has the pathology report and could have looked it up, but we decided against that.

We talked about the characteristics of the tumour that women identify as being important at the time of treatment and then seem to remember.

"It seems to be umm, the size is used in grading the tumour as well, you know, if it’s under two centimeters it’s considered umm, good, if they can catch it before, because after two centimeters they consider it large. In terms that it’s perhaps been there longer, because of the size of it. Yeah, so there is that size, whether there’s lymph node involvement. Maybe that’s because initially you’re focusing in on, on the ah, the physicalness of the tumour. Where it is and how big it is. And then you go for treatment according to that.

Afterwards, whether you’re going to be on the tamoxifen, and is determined if your tumour is estrogen receptor positive or negative. So that’s kinda later on maybe in the treatment. From my personal experience, now after the treatment we deal with that portion of the tumour. Positive so he suggested that you do the tamoxifen therapy afterwards, for three to five years. Maybe initially there is only so much your brain can handle you focus in on where the tumour is and how big it is and has it gone anywhere else. . . That’s the information that you’re hit with."

I asked Anne has if she has been thinking about the future since being diagnosed with breast cancer.

"The question is now, what will the situation be in a year? What about recurrence? You know, the pre-cancerous portion of your life, I’m sure it goes through everybody’s mind, ‘Will I ever get cancer?’ Well that’s been established now because I do, I did have cancer. So that question is no longer umm, to be thought of. The fact is, ‘Yes,’ now the question is, ‘Will it recur?’

Along with that is you know you think, well what will my life be a year from now. Will I be here five years from now, 20 years from now. So, from that standpoint you do wonder. You know and even if you have a positive attitude and you’re thinking ahead. And ah, you know planning events like a high school
reunion or a college reunion this sort of thing. You got, I personally can’t help but have those thoughts in my mind. The what if’s.

But it is important that you don’t umm, play it up too much. And you make the most of each day that you have. . . More of ah, I don’t know if urgency is the right word. But if, you know, before if you were thinking well if I don’t do it this year I can do it next year. Now you think well, I’m, gonna do it now because I don’t know. . . I caught myself the other day when I said, well we’ll do it next year. I thought, wow that’s rather bold of me isn’t it. What an assumption here. But it’s good, you know. You have to make the assumption I think that everything will be okay. Because you know, I wanna live until I die. I don’t wanna worry about when that’s gonna be.

Because 50 years from now, I’ll sit back and say jeepers maybe I shouldn’t have worried about that so much, just look at me now I’m still here.’ It’s different, it’s like a balancing act. When you’re looking into the future umm, those little thoughts do come to your mind. But you don’t want, don’t wanna play it up and draw that to be the focus."

The future has become uncertain.

"The last couple of months have been difficult. I think it’s, ah, perhaps it’s a bit of grieving or just taking count of things that have happened. A lot of losses. Loss of a body part. Loss of umm certainty. Loss of friends. That has happened, certain people. A total sense of loss of control. Loss of a job. Loss of that whole routine of going to your job and seeing those people, umm. Fear comes into it. These are things that I’m having to sort out right now. And it takes a lot of energy and it can get you down, and it can be really hard. . . You know this is probably one of the most difficult things I’ve ever had to do. It is the most difficult thing, because I’m reevaluating my entire life right now. There’s some things that you know are uncertain."

A couple of weeks ago Anne found out that her job at the hospital had been "deleted" due to a reorganization. Currently she is on long term disability and therefore does not have to worry about finding another job right away. She is very relieved about not having to look for work because she is not ready to go
back to work yet. She is sure that when she is ready to go back
to work she will be able to find a job.

"But you have to be careful that you don't let
something like this override the progress and the
building that you're trying to do to get yourself back
on track. It doesn't have to be a major wrench... No
it's not good timing. But, but on the other hand it's
wonderful timing. I look at it from that point of view
as well. I've always said if I was going to get cancer
this is a great time to get it, you know. The
economy's unstable. At least I know I have an income
for the next 20, 22 months. That really alleviates a
lot of the pressure to worry about, humm, my job.
Somehow it ah, it will all work out."

During the interviews Anne talked about her experience as
stages that she had passed through. I asked her to tell me more
about these stages.

"Stage one was when I found the lump. And then on
finding the lump you start to see the doctors... I
consider that the first stage the umm, the question
stage. What is it, what are we dealing with here?

I think the second stage begins when you're
actually told that there are atypical cells, it is a
malignant cell growth. That's when the word cancer
umm, it is cancer... It is defined at then at that
point... And then there's more tests to be done, in
terms of is it anywhere else. Has it spread... That's very difficult waiting for the results... You
know you're in trouble, but you could be in deeper
trouble, or maybe it's confined. So now it's in stage
two you're thinking about okay, umm, is it just my
breast? Is it somewhere else? What will the treatment
be? Will there be treatment? Am I gonna die... .

The avenue of treatment depends on what they find
surgically. There's another pathology report that they
wait for. Okay? Now, perhaps that's a substage of
stage two I'm not positive. But it's umm, because it's
just, it's like a triangle you have got the base with
all these questions and eventually you're trying to get
to that point the top point where you know what it is,
what you can do. And you start making finer decisions.

I guess closure of stage two is when I went back
to the surgeon. We had the pathology report from the
surgery, and it was established that you know the
tumour type, the size, was there any lymph node
involvement. Those were the crucial questions at this
point. That determined ah, the treatment. Because I had chosen mastectomy so there’d be no radiation in my particular case. . . When the Cancer Agency doors are open to me is the closure of stage two . . .

Stage three is when I walk through the Cancer Agency doors. Turn around have a good cry and go outside for a while. . . [The oncologist] tells you your options for treatment, and you decide whether you want to take that treatment or not. You have a choice. That’s the ball going when you say yes, and take that treatment that’s where stage three really starts to grow, when you start in on the treatments. And within the treatments themselves is where you get the substages. Each treatment is a substage I found. . . That each, each time you go in there it’s different.

The first time everything’s foreign, you don’t know what to expect. . . So physically and emotionally it’s a totally new experience. . . This is going to save me. I’m up for it. Let’s do it. . . And then two weeks after your first treatment your hair starts falling out. And that’s when I thought ‘Wow, this really is happening.’ That’s a definite sign post, that you’ve been there and had the chemo cause your hair’s falling out. So there’s an energy, a positive energy that I had. You’re really contributing to your own health here you’re going through this. You’re going to save yourself with their help. . .

Then after the second treatment I started to feel badly. Scared. Really grieving or hurt, that this is happening, you know. And you don’t feel good and really down. . . You just don’t feel well physically. . . And that kinda overlapped into the third treatment, too. But I started to, it kinda tapered off emotionally then. It became rather this is what I have to do let’s make the best of it. But I found it very difficult to be so tired and not feeling well all the time. . . It’s like wandering in a desert, you know. You know that after a few more treatments it’s going to be over but it’s, I guess the novelty has worn off by that point, so to speak. . . But you just, you just try to be up. You try to have some normalcy about your life. . .

Then after the third treatment you know that the fourth is your last, so things start to brighten up a little bit. You know your hair will start coming back. You know, you can get on with things. . .

The [fourth treatment] is interesting because then you realize wow this is my last treatment now, what do I do. I have to actively pursue something now on my own. . . Instead of a nice steel suspension bridge over
to society now it's more like this rickety old wood bridge were you're going, whoa, I don't know. It's like coming out from under mum's wing. We've done it, we've given you the treatment, there you go now. And it's frightening to come out from that. That's when I think the evaluation of your life, your psychological questions umm, start to come up. After the fourth treatment that focus of the physical aspect of treatment, of physically being at the Agency and physically getting your drugs, and being monitored is finished on that regular three week basis...

So now you shift into what would be stage four I guess... the insightful stage maybe... You've been redirected but you're not sure where to go. The emphasis is no longer on the physical... There's not a brochure at the Agency of good naturopaths to go to, or you know, vitamin supplements. You won't find that. That's up to you. It's like, it's almost like growing up again you know. It's a real growth period. So you have to do that.

Then on top of that which is the physicalness of taking care of yourself, umm, then you get into the psychological care that you require as well. In you know dealing with things that you haven't dealt with before. Looking ahead you know what do I want out of life, what is important to me now, after all this, what matters. And that's a really painful exercise. And I think this is the stage that I've been in for the last couple of months, you know, post-treatment."

During the process of diagnosis and treatment Anne kept in touch with people from work and her friends. She also met and talked to a number of other women with breast cancer at the Cancer Agency, which she found helpful. "Because although your friends and your family are wonderful and supportive it sure is different talking to someone who has actually experienced this situation."

During this time Anne spent a lot of time with two friends in particular. It turned out one of these friends she no longer sees. The relationship just "dissolved". Anne thinks this friend never had the capacity to realize what happened to her,
and Anne does not want that in her life. On the other hand Anne found there were a number of relationships that have grown during her experience. Anne described a pattern of what happened with friends and colleagues.

"There was a lot of people around. Eventually that concern, maybe not the concern itself but the calls and that, start to slow down, realizing that, that people have their own lives. It’s the same as the death of a spouse, or something you know how people flock around for a certain period of time and then after that, the calls aren’t as frequent, the visits aren’t as frequent. But, maybe that’s okay I think, because, it coincides with the period when you start to ask a lot of questions. And maybe that allows you to be honest and ask yourself a lot of questions, because you are not distracted with visits and going out. It gives you some more quiet time to dedicate towards yourself."

We continued to talk about the staging of her experience.

Anne talked more about stage four, where she is now.

"Now there’s this, re-directive or growth period. Evaluation. As one woman said, ‘Taking stock of the situation and what’s happened.’ And that’s so true, I like that. Taking stock of what’s happened. Try to put it into perspective... .

I’ve had a real hesitancy about going to see my family. . . So anyway I bit the bullet and I’ve got my ticket and going back. So that’s kinda nice. That’s been a major decision that I’ve had to make or I’ve wanted to make and I wasn’t able to make it for some reason.

This trip to me is a form of closure. In terms of going back seeing my family. Talking about this experience with them, there’ll be a lot of talk. It’s kinda like the cancer trip, you know. (laughs) Because I haven’t seen them I haven’t seen anybody except my . . . my mum and my sister in a year. . . So I think in going back home, and talking to my family, and knowing that, that they’re still there and their life is going on. And I’m basically the same person I was. It’s a nice package deal.

Go back and talk about it. . . And in doing so I’ll be able just to - to make some decisions. I’ve got a lot of decisions to make and I don’t feel that I can make them right now and I think that’s because it’s
it’s kinda, closed in or something. The area is blanketed with what has happened over the last year or so, and I need to be able to get out from underneath that blanket.

So I’m looking forward to it. . . I’m thinking will be the end of stage is it four we’re at now I think so . . . the end of stage four is the closure. And in doing that and in tying up all these ends, I can put it put the experience in the past. I’ll never forget it, you know. But you put it behind you to some degree and you move on, you know, with the future. Moving on your new life, you know."

I asked Anne if this was going ‘back to normal’ a phrase she had used earlier in our discussion.

"I don’t think I should have used that choice of words. I don’t like that word ‘normal’, back to normal. What’s normal? . . . it’s not really going back to normal because you can never go back to what you were before this happened, I don’t think. . .

Perhaps what it is, is that, your life doesn’t revolve around the cancer now. Instead the cancer is a part of your life. The cancer and the experience is a component of your whole life. You know pre, peri and post. . . Placing it in that part of your life, where it is, where it will always be. And every year when you go for your check up you go back to that little part, of your life. But it’s not the focus of your life any more. . .

But the goal of this focus and this reevaluation and redirection is to be able to put it in it’s proper perspective so that you can get on and live your life until you die. . . And not be preoccupied with it all the time. . .

It’s very difficult, I have found it very difficult. But I feel changes and I feel that there will be a resolution of it and I’ll find it’s proper place and I will tuck it in my heart and in my mind and. And I don’t have to dwell on it. There’s no point in doing that because you’re going to miss out on your life. I have to focus on the future. Realize you know what’s important, what do I want out of my life now, and go for it. Deal with the day to day things that come up like a job loss or whatever it might be.

By no means you’re going to live a flowery little life from now on you know, there’s reality. It’s a reality check, you know. It’s like a, it’s almost like a confrontation in a way. My reality now. What am I
Anne's experience with cancer has changed her life forever, not only in the present but also for the future.

"I don't like the word 'cure'. Because, I don't know, there is no cure. They say 'remission'. Well that sounds like, yeah, it's gonna come back. Words, you start to notice words a lot, expressions that people use. The rest of my life, I'm going to live here the rest of my life. Well, we'll see. Yeah cancer is very different in that respect. That's another part of the closure and the coming to terms with it, how are you going to look at this. Are you going to look at it from the point of view that, yeah, it's going to come back it's just a matter of time. Or do you look at it from the point of view that, I've got this thing beat, and I'm gonna get on with my life, I've got it beat. Even when you say that there's that little thing of doubt that pops in too. But there is no certainty, you know."

I again asked Anne to talk about what she thinks may cause cancer and more particularly what she thinks may have caused her cancer.

"Why I got it, I'm not sure. I look at my life previous to it and the last, probably the last three to five years were very stressful. A lot of major changes. Just a really difficult, sad sort of time. Personally, you know, things that were going on. And then I started to change about, you know, I changed some things in my life and within a year bang there was the lump. Just when I felt great. I thought that I was doing very well. And I look back now, and I have to wonder if there was a lot of denial or something going on there... I think what I was doing well at, were not important issues. I wasn't concentrating on the bigger picture.

So I, I have to wonder you know, they say that the tumour may have been there eight to ten years. But I wonder how I could have missed a lump that size. And I must ask my oncologist about that on Wednesday you know could this have come on quick, or did I just miss it. I don't know."
So, you know we don’t know, or is it just a physiological change in your body, but what brought it about you know. I have my own, kind of, there’s some coincidences I guess that I wonder about in terms of changing my life and, umm, you know, getting rid of some bad habits.

Actually, it’s strange because, I feel that I can say this, it was 13 months from the time that I had decided not to drink any more to when I found the tumour. And I often, so in that 13 month period I was dealing with this change and a relationship that had fallen apart. And as I said, I thought I had it together, but I don’t think I had it together at all. I think I was stressed to the max. After all the crap it was like a year of total absolute stress. Pure stress. And it wasn’t the type of stress where you say, ‘oh geez I gotta do this and I gotta do that’ or you’re worried about an exam and something a work is bothering you. It’s a higher level of stress. In terms of mental pain."

I asked Anne how the complimentary therapies that she is now investigating fit into her experience.

"There are some basic threads like the Asiatic or the florescence, these are herbal teas. In terms of umm you know, immune stimulants, immune boosters. Some theories or train of thought on this is that your immune system has been compromised and that allowed you to develop the cancer. In that we all have cancer cells. But if your immune system is compromised it - the cells multiply and you end up with malignancies. . .

So one theory being now you know if you take supplements after your chemo or after your treatment is to boost get your immune system kicked right in, and boosted it up, and then keep a maintenance program. Where it’s being stimulated or maintained for prevention of reoccurrence. . . Like the C, E the anti-oxidants that they talk about now in terms of, breaking down and being able to get rid of carcinogens that you take in through the environment and the food you eat.

And umm, I watch my diet you know. I try to eat, I try to eat your greens, your raw fruits and your raw vegetables. They call them live greens because they’re alive, you know. And you eat them and you take the energy that they have from the sun and put it into your

\[55\] Vitamins C and E.
own body. It's an natural sort of energy. . . So in putting these, these foodstuffs into you. In comparison to eating you know McDonald's, and a lot of, you know, fatty meats and things like this.

My line of thinking is well, it's alive, and it has energies in it. If you put that into your body that can only be stimulating for you. Healthy for you. There's no way of avoiding the contaminants in our environment, they're everywhere.

But I think if you are sensible about what you eat, I mean there has to be a connection there as well. In terms of disease and our unhealthy society, you know our dietary habits, smoking and drinking, our excesses. . . So you have to do what feels right for you. If I believe this, there is a placebo effect. There is that mind-body connection somehow. I don't think we've tapped into it. In my opinion there's a great awesome loving energy out there and we have to grab hold of it, and we have to bring that into our lives. . . These are avenues that I'm thinking of and I often thought of even before this happened. I knew there had to be a bigger picture."

At the end of the third interview Anne told me a story about how one day she was walking behind some men. She over-heard them talking about a friend who had bone cancer. "It's interesting no matter where you go, there is some evidence of cancer somewhere."

The fourth interview was in the middle of August. Anne had been away on holiday, visiting with her family. I asked Anne about her trip.

"I came back with, ah, sort of a different view of, you know, family is there. In terms of, I guess I feel I've grown up a lot, you know. Like, (pause) it was different and, you know, I really haven't been able to pinpoint it, I'm still kinda thinking about it. But it certainly was good to connect with the family, and spend time with my mum and dad. And that was nice. Although as I said I found it hard sometimes. But maybe that's just because ah, umm, I don't know. Maybe it's always been like that too, you know going back to visit."

I asked if she talked about her experience with cancer with her family?
"Umm, no, not really. That was kinda interesting, umm, not in any depth. Umm, (pause) and, well it depends, I talked with my brother, quite a bit about it just because of the mortality thing. And umm, death and God, and this sort of thing 'cause he's got quite a faith. So we spoke about that a lot, with him. Umm, and with my other sister of course we're always very close talking about things, but with the other sister it didn't really come up. I don't know that she's comfortable with it, or something, so we really didn't talk about it too much.

And I really didn't know that I was really up to talking about it all the time, I mean, you know, what's done is done. Let's get on here. With my folks we discussed it a bit, but we didn't go into any great details. So that was kinda interesting, you know. I didn't know how it would go.

And ah, my aunt and uncle who came up, umm, just for a day, had asked my sister, you know, 'Well what do we say to her? How do you talk to her, now?' They didn't know how to deal with me. They didn't know what to expect. So they asked Kathy's advice on what should you say, or not say. She just told them, 'Be yourselves. Treat her like you've always treated her, there's nothing, you don't make special conversations and stuff like that, you know.'

So it was interesting to see the reactions of people. Some people would jump right in, and want to know certain things, and other people it would never come up. Like the experience would never come up. And it was very black and white, in that respect...

And I tried a few things, like I would bring something up, or umm, just to see what their reaction would be, and, and I think it made some people uncomfortable some of the time. Like to say the word 'cancer', I mean some people, some people won't say that word... we'd be talking about somebody else that, you know, they knew who'd just died and just in conversation and that, and somebody that was going through treatment, or something that they knew, but, the, the disease itself would never be spoken of. So finally one day there was a conversation going on, and I said, 'Oh, well yeah he has cancer, you know you can say it. It's okay.' (laughter) Yeah, so there was no middle road there it was really interesting. It was either, yeah we'll say it and talk about it, or, no, we, we don't discuss it. So, so that was kinda neat.

Kathy is a pseudonym.
And I can go either way, I’m pretty flexible about things."

Anne had been home from her visit with her family for about three weeks. She said when she first got back she felt a little depressed. Anne feels she still has a number of things to work through, and needs some time to think about what has happened.

I asked her what she had been doing since she got back from her visit with her family. She said she’d been exploring the job situation. I asked how that was going.

"Oh, there’s not too much happening out there for full time jobs. Most places they either aren’t accepting applications, or if they are accepting applications it’s just for a casual basis, and it’s not in my area, anyway. And I don’t think the chances of getting back on where I was are very good, from what I understand. So that’s kind of a burden right now too. I’m trying to decide, ‘What am I going to do?’ I don’t particularly want to spend much longer on disability. The days start to get long. I need tasks, I’m a task-oriented person, type of thing. It’s nice to have an afternoon to sit around and read once in a while, or whatever, but not to have these blocks of time on your hands. . . It’s been okay, but I do feel it’s time to get back into the swing of things. Even if it is just a graduated program."

I asked Anne how her health has been since we last talked.

"Other than that [down period after she came home] I’m feeling good. Yeah. You know, and umm, trying to control my mind at times, so that, so that your thoughts so you don’t get dwelling on things, like dwelling totally on the job situation. Because that can get you down. You have to be able to stand back and say okay, well something will materialize, you know, have faith in that. Don’t let it overwhelm you because you’ll be taken care of anyways with the disability. It’s not that I have to have a job because I have no income thank goodness I do have that insurance.

But it’s interesting, umm, I thought about doing some volunteer work actually. And I thought about the Agency, and I decided against it. Because it’s still too close. You know, it’s only been a year since this whole thing’s been going on. And as well there’re women in the community that, that I’m in touch with
that have had medical crises either, ah, scared recurrence, or umm, possibly something going on inside of them in terms of nodes that have appeared, and this sort of thing. And, even like when you watch the news and, you know, somebody dies, a movie star or something, they always say, if it's cancer they died from they always say that. So, it's, it's, I don't know, and I find it hard at this stage to listen to it.

And I think it's, again, it's maybe it's just too fresh for me, and I don't feel, you know, 10 percent confident about the situation yet, and as time goes on and you develop a confidence, I think. But right now it's still so new. You know, often times if somebody's telling me something I don't want to hear it. I don't want to hear about the recurrence or that somebody's died, or this and that.

So I've decided just to back away for a while, and give myself time, so I won't be doing any volunteer work there. You know, and I think that's a self preservation tactic as well. It's an individual choice. But for myself why would I want to put myself through that day after day, or whatever, listening to this sort of thing. Because inevitably I mean it, it triggers little thoughts in you own mind. So in time I would like, umm, to be involved but I don't think right now is a good time."

I asked Anne if her experience with cancer was still very close.

"In some ways, yeah. In other ways I feel that it's, it's distancing itself. Well, I can say that, right now you know I've, it's been a year. So that's good. There's another year under my belt, that's good, that makes me feel good. So those are positive milestones, I think. Positive things that are happening, umm. And that's good.

But it's, it's, but I guess it's still close in the sense that umm, that's easy to deal with realizing that you've come this far. But it's, you know, but, but when you start to hear about somebody you know who's being checked out for something, or they're having medical problems, umm. Then automatically the situation is brought into your lap again, and you think, 'Gee I wonder if, this is going to happen to me?' So I think in that, in that situation, in those situations, there's still some healing time needed so that you're able to get over that hurdle and say, 'Well, every case is different. This isn't going to happen to me.' I can say that to myself but it's still shaky ground, you know. Like my legs are still a
little bit wobbly to be, umm, yeah. But as I said it’s been a year and, and that’s good, so.”

I asked Anne if she had actually marked the date that one year was up.

"Yeah, well it was important for me to recognize it, you know. Because, the date that I actually found my lump, was, you know, when this whole thing started. So there’s that date, and there’s the date that you went in and had the tests done. And then there’s the date you were told yes you do have cancer. And then there’s the date that you had your surgery. And then when you started your chemo, when you finished your chemo, the stages that we talked about earlier. Umm, so I don’t, I don’t, I mean, I don’t celebrate all these dates, but it’s in the back of my mind and perhaps in time they’ll be just one or two days that you’ll remember more.

You know when I look back over the year, I think, wow, like last year at this time I was, you’re frantic, you don’t have any answers, you don’t know. At least this way, now I know what the situation is."

Continuing to talk about the passage of time, I asked Anne to talk about the stages she had discussed in the previous interviews. I asked if she was currently still in stage four, or if she had moved to a different stage.

"I’ve moved into a different stage now. From probably after treatment until, ooh, Mayish, Junish, before I went home, and actually I had a hard time making a decision to go home because I was in the next stage where I was dealing with a lot of anger, and umm, rage. Not quite sure who to direct it at, (laughter) or ah, ah, it’s really an internal thing. I guess I was mad because I, I had had cancer, and I was mad at God for, not questioning him as to why did this happened to me, but wanting to know the purpose of it, and not having any answers in that respect. And just the uncertainty of everything. So there was a lot of rage. And I was sharing a place at the time and it really wasn’t working out that well. Umm, I just felt blown apart. And very sad, as well. A combination of rage and sadness, you know, it was quite a dark time.

Umm, I guess this is quite common. The period after treatment, you’re done your treatments, and you’re left to pick up the pieces now. There’s not really any, in my particular case there’s no real
definition of what I should be doing now, because I don’t have a job. So it’s not like I have something that I can say, ‘Well, I’m ready to go back to my job now.’ You don’t have that to go back too, that’s just another stressor . . .

Yeah, in effect loosing my job was a great loss. Because it means that I don’t have that familiar setting to go back to now. I don’t know where I’m going to go and I don’t know what I’m going to be doing. So that security that you could return to and get on with things, because you know the people and you know your work, it’s not there. I don’t know who I’m going to be working with now, and I don’t know what I’m going to be doing. And I was mad as hell that I lost my job.

That stage has been, I guess dealing with umm, the reality of, of getting on with things. Returning to, to work and ah, and emotionally it’s been just a roller coaster for me. I feel it’s somewhat levelling out now, even the trip was, was it was very tiring, it was hard, like emotionally. ‘cause I wasn’t quite sure of my new identity. I was sure pretty much within myself, but then umm, I guess it’s so easy to, to be someone you’re not, or something. It was interesting. Just in terms of looking at the situation from my point of view now, ‘cause I’ve had the brush with the disease, and so I can see things from my point of view now and justify them. I guess there’s a justification period, I don’t know. (laughter) Yeah, so, I guess the trip, it did satisfy a few things in my mind, yeah. And it’s given me a clarity about certain things in my life now and which directions I’d like to take.

I think the trip umm, finalized the rage stage. Yeah. Now I’m in more to, think I’m somewhat calmer. You know, still looking for answers, a few answers anyway, but I’m a little bit calmer. Because I don’t have that rage. And that rage was so difficult to deal with. Where do you put it?

I’m also going to, umm, I think, link up with umm. I don’t belong to a church, I don’t have a church, but I’d like to link up with some, you know, spiritual advisors, or somebody that knows the bible and this sort of thing. Because I have some questions. You know, and this has been, and this has really brought close to home some questions in terms of, of my faith. So I’d just like some answers and I think the best thing to do is just to go to the source basically. . . So that’s what I’ll do as well. So job and just clarifying a few things in my mind, and ah. I think it will be an exciting time and I’m kinda looking forward to it."
I asked Anne how her investigation of complementary therapies was going.

"I haven’t spent any time investigating any of it, at this point, further investigation anyway. I’m still just doing the supplement routine, you know, with my meals. And I still watch what I eat, I try to eat better, umm. But that’s hard when you are travelling too... But no, I haven’t, I haven’t looked at anything else at this point in time. It kinda goes in fits and starts too, you know. You get a sense of when the time is right to pursue that. To elaborate on that a little bit more."

Anne has been reestablishing contact with old friends since she came back from her vacation. This has been very nice. She finds getting in touch with people "grounds you a little bit".

I told Anne that I did not have any more questions and asked if she had anything she wanted to add. There was a long pause.

"On my trip, and on my way back, I kept hearing a song on the radio, or where ever I was. And it’s an old Supertramp song and I use to, I remember when I was in my early 20’s I bought this album and I always loved this song. But I could never quite understand it. So I heard this song a number of times on my trip, and the song was ‘Take the Long Way Home’. And I thought, perhaps in some ways that’s what I’m doing, or that’s what I’ve, or that’s what my life is, you know. Finding the home within myself. Doing it in a rather round, or broad way, you know in terms of going through this disease, and then having to look at your life and evaluation, and finding out what you’re going to do. The long journey."

I wondered if she saw this journey as having an end point in the future.

"I think it will. Not a total end, but it won’t be, it will be more of a, ah, a point, like. Right now, and up to this point my whole life has been encompassed with this disease. So, as you move on and settle some things in your life, and come to some understandings I think it reaches a point where it’s just a refined perception of what’s happened. And you’ll always have that with you, and you can always draw on it, but it’s not as all consuming as it has been. There’s a place for it in your life, but it’s
not the major focus of your life. It's just an awesome experience to go through. Like a great trip, around the world trip or something. It's that sort of thing."

I asked Anne where the cancer was now in her life.

"Umm, I guess I’d have to say I feel that it’s, it’s kinda mid-point right now. Although I have days where it’s more, ah, more right, ah, kinda in my face, other days it’s not. Umm, yeah I’m not quite sure. . . A little more recessed, in my mind. I think some of it is a conscious effort to, umm, to allow it, to allow yourself to let it go. And not, to prevent yourself from hanging on to it all the time. Because I think, I think it’s a very good possibility that, that could happen, where you’re, you’re just clinging to it. The disease itself might represent a sense of security to you. You know, I don’t want that. I don’t want it to become something that I need. I don’t want that.

I want to, to let it go, to put it in that little compartment. You know I can tap into it and help people and learn from it and allow myself bad days when it sneaks forward. But I don’t want it to be there all the time. So, I guess it does, perhaps it takes some conscious effort. But I think that’s when you get into, to coming to, to decisions about your life. I mean if everything is up in the air right now in terms of job and money coming in, and future, and that, it’s unnerving, so it’s easy to equate that sense of being worried and bringing the cancer again, so you’ve got everything to worry about. Okay, whereas once things start to develop in my life now, and I get on with it. Then there’ll be other things for me to focus on, and to put my energy into. The cancer experience will always be here, but it doesn’t have to come along with everything I do now.

I don’t know how I would have, I don’t know where I would be right now, if I had my job to go back to. The situation, I think would be quite a bit different. . . Because I could get things moving faster. And there would be a calmness in knowing I’m going back to people I enjoy working with and the job that I like, you see. So, although you’re nervous maybe about going back to work, you know, you get a little gun shy now, because you’ve been out of it for a year and you hope your skills are up, umm, a little bit less confident than I was a year ago, you know. Little bit insecure in my skills and just knowing, that, I know I can do it, but jumping in again, you know, getting your feet wet again is kinda scary.

And now I don’t know where I’m going to be doing it, or if I will be doing it. So that security’s gone.
But you know maybe it's just another redirection, the disease did it totally redirected my life. A lot of good has come from it. So maybe it's time to umm, have a look at some other options in terms of what I want to do, job wise. And we'll see what happens. It should be interesting. Very interesting. But I feel that things will work out, I think, it will be okay."

At this point I stopped recording our conversation. We talked for a little while and then said good-bye.

B. Rebecca

Rebecca's story starts in much the same way as Anne's. One main difference between them is that Rebecca had been previously diagnosed with Parkinson's disease. This introduces complications and frustrations into her story of diagnosis and treatment.

Another main difference is the way Rebecca talks about the position of the cancer in her daily life. The predominant feature of this is that Rebecca describes the cancer as being the endpoint in her life, the conclusion of her story. She does not use the cancer as a point of reevaluation, but as a point of contemplation. This is a schema shared by other participants.

Rebecca is unusual in that she does not develop a personal risk profile, as she is not interested in what may have caused her cancer.

Rebecca is in her late 40's. She is a professional woman, with a post-graduate degree. She was diagnosed with breast cancer about ten months prior to our first interview. She participated in two interviews, one in May and one in June 1994. Both the interviews were done in the living room of my home.
Rebecca is interested in the sociology of medicine and has read in the area. This interest was one of the reasons she volunteered to participate in this research.

As we started the first interview Rebecca asked to sit in the corner of the sofa so she could use the arm rest. She explained she had Parkinson's, and one arm was quite weak and she liked to sit with it supported.

The first interview started with me asking Rebecca when she was diagnosed and what happened.

Rebecca started by saying "It was a very unexpected finding out." Rebecca had been for a regular check up with her family doctor in June 1993. The doctor found a lump in Rebecca's left breast, and sent her for a mammogram and a needle aspiration. After having the mammogram the radiologist felt there was no problem, but suggested Rebecca should have an ultrasound just to be sure.

"In the procedure for the ultrasound she didn't find anything where my family doctor thought there was something, but she did find something on the other side and she called it a mass. I'm always interested in sort of the terms that people use here but she called it a 'mass'. And she knew it wasn't a cyst so she thought it was worthy of a pathologist's look."

The radiologist gave Rebecca two options. She could come back for a needle aspiration either on the following Monday or in six months. "The term mass has certain ominous overtones, probably unnecessarily so, but anyway I chose the Monday."

After the needle aspiration Rebecca had to wait for the results.

"And a week, a week's wait later. Which was, I think it was a fascinating week because it was a lot of talking with friends, and a lot of dealing with waiting
and anxiety, and I read a lot of material during that week. I think in terms of, umm, preparation for whatever, I felt it gave me a little more feeling of control. And, umm, and I basically believed everything would be fine, because I didn’t see any reason to think otherwise.

So a week later it was determined that in fact it was cancer, and the, ah, the next step was to have an operation to determine whether it had spread to the lymph nodes. So that’s, in my mind that was the first glimpse into the world of breast cancer."

I asked Rebecca how she came to the understanding that nothing was wrong.

"Well, I think it was a combination of general orientation to life, and I think more to life than to society. And ah, which for me has always, always been an attempt to view myself as one part of human kind, one of many, but unique in my own way, my own cellular way, or own emotional way ... I wanted to combine a umm, feeling of uniqueness given that I was in that circumstance with a feeling of being one of many. And the one of many I think fell into the category of reading, and, ah, the uniqueness fell into the category of talking with friends. And what my, my mind was telling me which was, don’t worry about something that you haven’t the facts about."

Despite this understanding that nothing was wrong, Rebecca was dealing with a lot of anxiety. "It was dealing with it, it was like it was a volleyball or something. The anxiety, no there was no attempt to rid myself of it, but to deal with it in someway."

It was July by the time Rebecca learned the results of the mammogram from the radiologist. Then it was a matter of finding a surgeon. Rebecca’s family doctor was on holiday for July and August, but that was not a problem. Her family doctor’s replacement referred her to a surgeon her family doctor had on file.

Rebecca went to see the surgeon. "So that was to me, also,
a step into another reality." At this point she still did not feel any undue anxiety.

"I know I used the term 'adventure' with somebody and they were quite surprised, because I think there was a positive overtone to the term adventure. But it wasn't to me, it was more just these were unexpected turns in life, and I really believe that and you deal with it in some way and that's the adventure. So, and knew I had a lot to learn. When I think back on it I think 'oh how naive to even say something like that,' because it was really just the tip of the iceberg, because I think it was contacts with other people who had been through their own experiences that I had found the most valuable, and were real insight could be gained."

When Rebecca went to see the surgeon her husband Neil came with her. She had to discuss with the surgeon the implications of the surgery for her Parkinson's. A date was set for the surgery. At that point Rebecca felt again "... it was another world to step into."

It had been many years since Rebecca had last been in hospital. She had lots of support from her friends and her family. Her sister who lived in the United States travelled up to Vancouver to be with her.

"It makes it sound like a party. But it really wasn't, but it was in some ways. I think I found in that other people close to me were really entering into it, and people who were not close to me were more sending me cards. That always fascinated me about people's response to what happened. And my peers who also have Parkinson's, which was diagnosed three years ago, were supportive in their own way because they knew the difficulty in dealing with a chronic and debilitating illness that won't go away. And since cancer won't go away there, I think, there were some similarities in some respects.

At that point ... what I was hoping for medically speaking was that there would be no spread, and ... I would be able to dispense with chemotherapy and other things that would be potentially debilitating."
While she was waiting for her surgery she wrote poetry. Rebecca had never written poetry before, and felt that some of the poems were really very good.

"I realized that as social beings, we're such social beings, but in that situation it's so lonely. It is really lonely. And no matter how many friends it still comes down to the existential dilemma. . . I don't know why because, I suppose because it was my body, and my life, and my life as part of other people's lives, but it was also just mine and so it was a certain sense of being fragmented maybe."

Before her surgery the surgeon visited Rebecca. He asked her if she would mind if her surgery was delayed for an hour. The surgeon wanted to move another patient, an older woman who was extremely anxious, ahead of Rebecca.

"Part of me thought how does he see me that he would say that this elderly woman should bump me in line and yet part of me felt if I were 90 going through this I would be anxious. It was interesting . . . I felt I couldn't say no, what am I supposed to say?"

The extra wait was difficult. Rebecca did not want to have any drugs before going to the operating room, so she could talk to the surgeon. She described the operating theatres as "cattle stalls" with the patients being put into the stalls. The effect was they "fit the pieces into place and make it feel mundane and not special."

Later that day, after her surgery, Rebecca had an allergic reaction to morphine. She became very sick. A friend told Rebecca afterwards that despite being sick and groggy Rebecca had asked her friend to exercise her left arm, the side of her surgery. We laughed at that.

Rebecca found that having friends visit in hospital made her feel like an entertainer, which she found was very tiring.
Rebecca told me that just before her surgery she and Neil had bought a new house. So while she was in hospital after her surgery Neil was bringing documents for her to sign. "It was also sort of symbolic of the new life in a way. It was a decision, and I wasn’t there to do any of the work."

After the surgery there was another waiting period for the pathology report on the lymph nodes.

"There’s a chunk of time from there to diagnosis. Full diagnosis was another week, and then I knew what was ahead of me in terms of further treatment, and what that meant in terms of work, and what that meant in terms of health, and those kinds of things. I had no idea what it meant in terms of interpersonal stuff, but that I learned along the way, meeting other people. . . So, I realized in ten days that I did have spread to the lymph nodes and I had a type of cancer that wasn’t all that common, umm, and presumably spread easily and so on. . . So I wasn’t happy about that, but that was the way it was so it was then going to chemotherapy, and working out all the medical details in terms of my Parkinson’s medications, and all that kind of stuff. So I suppose that’s kinda of a first chapter of sorts."

Rebecca had a segmental. About 20 lymph nodes were removed. She found the surgery very disabling. However her arm did not swell.

"But with my Parkinson’s, again, it’s interactions all the time, because it’s mainly in my left side, although it is also my right, and so with that with that stiffness is also created more pain, and more disability in terms of flexibility of the arm and so on. . . It’s still very sore and that’s quite a long time ago now, nine months or whatever. That’s a good point, I mean that’s sort of like the lowest level of experience, but none the less it’s a serious one

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57 A segmental is the removal of the lump and some surrounding tissue, it is the same as a lumpectomy. The amount of breast tissue removed is up to the surgeon (Love 1990).

58 With the removal some of the lymph nodes from under the arm some women will get lymphedema, where fluid collects in the soft tissue, causing swelling (Love 1990). There were a number of women who had serious problems with edema.
because it affects your day to day life. You know you
can’t reach around and grab your seatbelt in the car or
whatever. There’s reminders all day long that I have a
couple of incisions that make my body feel
uncomfortable."

With the results of all the tests Rebecca and the surgeon
decided she needed chemotherapy. So Rebecca was referred to the
British Columbia Cancer Agency.

"It’s absolutely fascinating because all these
things happened, with unknown participants. I mean I
didn’t know who I was being referred to. I’d never met
the person in my life. Of course I always knew I could
dump them if I didn’t like them, but it was still kind
of a plunge into, into that institution that I’ve
always visited people in, but never been a part of.
And umm, a friend of mine had died a year before of the
same thing, well the same in the sense of being a type
of breast cancer. My mother had died of cancer, and
I’d known a couple of other people along the way, but
it was now my turn. Which is quite different."

Rebecca described her first visit to the British Columbia
Cancer Agency.

"To sit in a waiting room with people who all had
cancer, and nobody was speaking, was really something.
All those people sitting there, and maybe they all
didn’t have cancer but umm, most of them probably did.
. . Thinking of what I know now, what I’ve experienced
now, and how I view that institution versus then, I
never felt like a victim but I felt a neophyte, really
a neophyte. I didn’t - I was just going into it as an
experience. On reflection I guess I’ve learned more."

Rebecca started her chemotherapy a week later.

"Which is another realm as well . . . The people in
the waiting room there seemed, quite, I remember, sort
of a less depressed feeling than, maybe it was because
they felt that there was something being done for them.
Whereas, in the clinical waiting room it was kinda like
everyone looked like a potato. Just sitting there . . .
I really didn’t feel, I felt more anxiety after the
first one than I did for the first one [treatment] as
an unknown. I felt the most anxiety, the very most
anxiety between my third and fourth treatments. And I
don’t know why, but I just didn’t wanna go back."
Rebecca got sick with her chemotherapy, just like other women she has talked to.

"I think my personality was directing me to just get through it. And not, just put experience aside, and just get through it. And the radiation would be easy in comparison to that. That was my attitude. It really was horrible."

Before she started her chemotherapy Rebecca was given choice of having it for either four or nine months. In the case of the four month treatment the drugs would be much stronger dosages, and it would entail losing her hair.

"Of course I wanted the shorter one... It’s a very alienating experience. I mean the best part of the experience, I found, was actually being there being administered the drugs. The most alienating part, I think, was after just feeling chronically nauseated for four months. And umm, and having skin break down and all those other things that happen... I just didn’t feel that I was, I was a part of what normally goes on in day to day life.

But also, I think, I felt that this was the route that had to be taken. So you know, I take it. That’s the way it is... To go through all this, and not to be able to be told you’re in remission, or you don’t have it, to not know, that is really asking a lot of a person. But that’s all they have. So, so when it was all over including the radiation and people said ‘Well are you in remission?’ and you say ‘Well, I don’t know but I hope so.’ I mean, it’s really crude."

Rebecca felt very fortunate.

"I had people around who, enough people to understand that it was an acute and unusual period in my life. And the people who felt that they couldn’t handle it, just didn’t participate, and that was fine.

It also struck me, during that experience when I needed to talk to friends, and so on, the differences in response to illness. And the sort of, the false reassurances that people feel that do such good. Oh, such as, ‘Oh, you’ll be just fine.’... It’s just classic protection really but ah, but my way of responding was usually that, using the facts, and ah, statistics, and I’m alive now and that’s all that matters, and so on."
But umm, I think stories of, cancer stories are all over the place. And it’s the good ones that usually get talked about, as a spirit lifter, I suppose, a spirit lifter of those in the middle. . . I didn’t have any patience with any of that stuff. Although now, I’m finding I’m more tolerant. Because I know people are afraid now, at that time I didn’t have the empathy, I didn’t have the energy."

I asked Rebecca to tell me some of the "spirit lifting" stories she had heard. She explained the ones she heard were from individuals rather than the media.

"Oh, my mother lived for ten years. And I would think to myself okay do I just let this go, or do I deal with it the way I really feel. And it would depend on the person. . . Sometimes I felt just downright annoyed, but then I got rid of that, and I realized that we’re all kind of self protective in a way."

These stories were a way for these people to protect themselves from the reality that they might also get cancer.

"It’s not acknowledging that cancer is around us. And cancer has an image, has a face, and it’s not a good one. But that umm, but even though it doesn’t have a good face they, you know, comments like ‘Oh, you’re the strongest person I know’ as if that would help me get through, umm, the longest number of years I can drag out of this thing, or make me feel better, or whatever. . . Then I realized pretty quickly that there’s this train of thought that actually one can take some responsibility for their illness, which was even more bizarre to me, and it was just amazing."

I asked Rebecca to talk more about this idea of taking responsibility for your illness.

"I guess people wanted to say to me that I may not feel in control, but really I could be, and if that were to happen logically, umm, then I would feel better. ‘No, no that’s not right’, that was my thinking, I was saying that, maybe that by taking responsibility, like exercising and doing all these lifestyle things, that just makes a person feel good.

But the links that were being made that I thought were totally illogical were things like if you meditate three times a day you can fight back the cells, and there’s evidence for this, if you join a support group
you’re going to live two years longer. I mean it’s just all these stories. They abound, they absolutely abound. I just found that it’s garbage, it’s just garbage, even if there were evidence, it is still just evidence, it’s statistical.

So okay, so here we are again, the same dynamic as people trying to help, and trying to fend off the fear that abounds about having a shortened life. Whether from me or for them. But at times it was pretty bloody annoying I mean it was wasted time to me."

After talking some more about the positive cancer stories, Rebecca continued to talk about her experience.

"So there you are completely hairless, and it’s time to go into radiation with, with male technicians. And it’s by that time I think physically and emotionally some people feel like they have something stripped off them. And I certainly did too. And that kinda in a way made it easier to go through radiation, ’cause I felt so totally unhuman by that time. I mean even though I think I struggled with it, and so do others, I know that it was just as well that you feel like a piece of shit by the time you get to radiation. People who don’t go through chemo don’t have that benefit."

Rebecca found that radiation was manageable, but again having Parkinson’s made treatment more complicated.

"Because of my Parkinson’s I couldn’t get my arm in the proper place and so on. So there I was trying to educate people about what Parkinson’s is, and why I can’t do certain things, and so on, and so forth... That’s a perception problem though. It’s a perception problem they knew the facts, but they could not perceive me as having a movement disorder."

I asked Rebecca if she thought the perception problem was because she was young and young women are not usually disabled. She agreed, and felt that more help might be extended to an older woman because an older woman would be expected to have difficulty in moving her arm above her head or getting up on the stretcher without assistance.

Rebecca had radiation therapy on 16 consecutive days. She
had a reaction to the radiation therapy.

"They said that, that would start at three weeks after going through the radiation therapy. And I must say that was the one thing everybody was accurate on. That three weeks after I got a lot of fatigue, and my skin started to peel, and I felt quite sick, and so on. And after, it took about three months, and then things settled down."

Rebecca asked her oncologist for copies of her medical chart. The oncologist refused to give them to her, so she obtained copies directly from the Department of Health Records at the British Columbia Cancer Agency. She found the attitude of the oncologist "patronizing".

"A hierarchy like the Cancer Agency were, were there’s the do-gooders and the people who have been done good to. What aggravated me the most, what concerned me the most, was the inability to see patients as peers. . . Yet we’re the ones that keep them in their damn jobs, you know. And we’re the ones that really know what it is like, and they’re the ones who have the scientific knowledge which we need so badly. And it’s a perfect partnership, it’s a perfect partnership, but it doesn’t take place. It’s astounding. . .

Where on the other hand, you’re told to, umm, to do all these other things like lifestyle, and look after yourself, and whatever. And yet some women don’t even know what type of breast cancer they have, they have no idea. They’ve never even seen the pathology report. . . That’s hard when there’s low energy to fight for your files, and that was me for the piece of paper, and I succeeded but it took a lot of energy. And I still don’t understand it, I really don’t. Well, I understand to the extent that I think that cancer has made some progress in coming out of the closet, but, but not very much. And I think it’s all wrapped up in this secrecy, and over-protectiveness of women."

Rebecca talked about the idea of forming a partnership between the patient and the physician.

"Although I think that the medical establishment is still divorced from, I mean I don’t think it is pushed as a value that helps with healing. But it’s in the literature, but it’s not in day to day life. . . It shocks me because it’s a resource that, umm, medical people aren’t picking up on. That their patients
actually could offer them some insight into what they could suggest. . .

I was the one who informed him that one of the drugs was contraindicated with Parkinson's, well he didn't know anything about Parkinson's, and so I gave him the name of the neurologist that he could phone and find out, which he didn't do. And so, as a consequence, I suffered with one of the drugs that I didn't need to.

But then it comes back to do you wanna live, or don't you wanna live, you know. And of course that's number one, of course I want to live. But I don't think it's that simple."

Rebecca went on to talk about the side effects of treatment.

"Side effects are not considered valuable really, it's more prognosis I think. That's the oncologists' view that's were they're at. . . I just think there's not a value placed on knowing. 'So what, so you're telling me that you threw up all day, well, what did you expect from the drug?' Or that's what happens. And, this is what is needed to go through in order to live as long as you possibly can. . .

But from the patient's point of view, not the doctor's point of view, it's a whole different story isn't it? It's the day to day existence, and it's very critical to happiness, and other things. That wasn't a new experience but ah, everybody many many people seem to feel that. And it is hard with an illness that is either chronic or life threatening. It's harder because every moment does count.

So for me I think in terms of illness and having Parkinson's it was, it was kinda like two things within me sort of warring with each other. And umm, and meeting other people who didn't have a second illness and were still finding it difficult and that provided a good measure for me in terms on not expecting too much of myself. That's at a very personal level. . . So in terms of the cancer experience I think without certain key things such as a sympathetic G.P. 59 as your advocate, umm, a good living situation, not having serious money problems, umm, whatever it happens to be to me sort of comprises, well that is the survival circle. These things for me were really critical in getting through."

59 G.P. is short for "general practitioner" or family doctor.
Since completing her radiation therapy Rebecca has not had any further treatment. She is taking tamoxifen. "And that is a drug with lots of side effects, of course, which is not, it's just considered part of the picture."

Rebecca is currently involved in two support groups for women who have had a diagnosis of breast cancer. One group meets once a month at the British Columbia Cancer Agency, the other meets once a month in one of the member's homes.

"So that's a continuation in a sense, but it is a continuation with the emphasis on life rather than treatment. And where there's mutual respect of each other which is often different than an institution. So as far as cancer experience, it will go on, and on. I suspect it will go on, and on, and certain people will come forward for a while and then there'll be a meeting of the minds, and then that will recede and something else will happen. You know I can see that kind of movement over the next while. And I think as I distance myself from the clinical experience I think there will be more understanding on my part about what it was all about. And what it might be the next time. And what it is for people going through it right now."

I asked Rebecca when she started going to the support group. She replied she went to a drop-in group at the British Columbia Cancer Agency almost immediately after starting her treatment. She asked if they had a support group for partners of women with breast cancer, because Neil was interested in attending a support group. A group for partners was started, and was very successful.

Rebecca wanted to start going to the support groups early in her treatment because she was concerned she might become too sick to attend later. Attending a support group fit with her personal philosophy of the importance of grassroots organizing and learning from others. However, she commented that the notion of
an illness bringing people together has its limits. From her experience with both Parkinson's and cancer she found there are certain people she will draw out of the support group. She will link up with someone who is a "soul mate".

I asked Rebecca how she got involved with the support group outside the British Columbia Cancer Agency. She explained she asked the social worker who runs the Agency's support group if she knew of any groups outside the Agency. The social worker introduced her to the group she now participates in. This group developed from a group of women who had been in treatment at about the same time. She described this group as being "part social time and part cancer time", whereas the support group at the British Columbia Cancer Agency is more down to business.

"It's a weird kinda feeling in terms of time, because I know as time passes, and has happened already, people do drop by the wayside. And that's part of the reality as well. So, whereas with, say, a Parkinson's support group you know that you're going to try and help and be helped as time goes on, and things become increasingly difficult. This way it's more losing, you will be losing people along the way permanently, and so I view it as a, we often talk about this, we view it as a present, but future experience at the same time. And to try and reassure ourselves that we know the medical facility is not going to be by our side at our death bed, they will not be there, they will be out dealing with new patients. So by getting to know each other now that support can be right at our fingertips. I tend to talk about it a little more than others. But I think it's implicit, I think it's implicit. Right now is a good period of time because we are all kind of recently finished. And we'll sort of see what happens."

I asked Rebecca if women leave the support group as they get further from the period of active treatment.

"No, I would say quite the opposite, because I think now what has happened is as we're moving away from the institution from the symbol of it, or whatever it is, umm, the reality of living with an illness that
nobody can really see. And umm, and that creates certain changes with a person in a previous life, a pre-cancer life, that sort of thing. And what’s of great concern to many women is to sort out who are we now, and what do we identify with, and how do others see us. And ah, because we’ve been through traumatic bodily changes that have been, that have hurt, and that are not going to be retrieved again. So that’s, that’s even more potent stuff than the treatment really, because living is harder than dying. And that’s what we talk about a lot.

So, and there’s never any easy answer to it, it’s more just trying to get a grasp on what part of you have - what part of us have we dragged across the coals, and what part of us have we left behind, and is there a corner that’s new, that’s completely new. And everybody has a different experience of that. I think the illness is still, is very ever present, but not in an acute way, but as a chronic problem, social problem."

Rebecca described what happens in the support group.

"I remember early on the concerns were very much linked to treatment, and ‘what is going to happen to me?’ Very much so, and I was there as well. And somebody else who had just been through that stage would lend assistance to that person. So it was very much a kind of immediate management of something overtaking their lives, our lives. . .

This seems to be a common theme ‘I’ve finished treatment now who am I?’ Immediately post-treatment ‘I don’t have a radiation appointments to go to, so what the hell am I gonna do?’ or something like that. And probably at that point, well that’s a real struggle, that’s a real struggle people as they are suddenly starting to sit back and think about what has happened to them. I don’t remember doing that actually myself, but I understand that totally.

And then it started on this support business. The support that was given to us when we were critically ill, and throwing up, and losing our hair, and the support that’s given to us now. And some women have said that they feel that they are not getting any more support because they’re finished, so perception goes. And yet this is the time when support is most direly needed, I think. But the communication doesn’t allow for that, so women talk about friendships, or whoever you’re living with umm, those kind of issues come to the fore because that’s when people they’re feeling a real need for connecting to the real world, and it’s just at the time when people are starting to simply
withdraw. The non-sick, the non-sick are withdrawing from this."

I questioned Rebecca about saying that she did not feel this post-treatment let down and questioning of herself.

"I recall thinking it was nice not . . . going to the institution for radiation. It was nice not having to go. So I felt that sense of free choice that I could now do what I wanted to do, which is to resurrect some of the things I wanted to do . . . I guess it's because I thought that up 'til that point I think everything had blended one, into the next, into the next, and now into the next, so it wasn't kinda like a block that I could draw like a square and the end of radiation and now there's THE FUTURE. It just didn't work like that with me . . . I felt that it went quite smoothly, and I, of course, I really didn't feel well until three months after radiation anyway . . .

Certainly for me in terms of getting on disability insurance and all those symbols of a change in life are very difficult. And umm, my G.P. asked me 'Do you want to go back to work?' I’m somebody whose loved their work, always loved my work. And I said 'Really I don’t know, I mean I don’t know.' I know now I couldn’t do it, but as I get my energy back and as the Parkinson’s progresses, and I have a fairly major sleep disorder. . . related to the Parkinson’s . . . Anyway that is part of the reality of the previous life that everybody goes through. And those that don’t have jobs probably have a harder time of it. So it’s uncertainty, continuing uncertainty is really hard. . . I think the major part was just dealing with the concept of mortality and those kind of issues."

I asked Rebecca to tell me about her Parkinson’s. She explained she had had symptoms that she did not understand. It took six months to diagnose the Parkinson’s, and that was an "anxiety producing experience".

"Although there was no operation involved I suddenly saw that my future was really not predictable in some ways, but now infinitely predictable because there is no remission to the disease, and the drugs that people take for it are very short term effects and they make you very sick. I guess, I in a way felt like a tree you know. There was no fixing it, no fixing it, but there was an accommodation that was needed. This was how I viewed it, accommodation that I needed to include that in part of my identity, as part of my
identity. And to be the sole, the sole decision maker about what drugs I'm gonna take and what drugs I'm not, and nobody was going to have that control, although I need the neurologist to write the prescription."

After being diagnosed with Parkinson's Rebecca needed to meet someone else with Parkinson's. She called the Parkinson's Society and was given the phone number of a person who lived in the suburb of Langley.

"That to me was a real life line, it was a real life line, and in a way I guess similar dynamics to the cancer experience. But from the diagnosis - the diagnosis was immediate alienation, a feeling of aloneness, or am I the only one, that sort of thing. And then realizing that it's not a nice disease to have. Those two things together. And am I going to be who I'm going to be despite the illness, or am I going to change. And what will it feel like and all those kind of questions.

With the cancer it was really simpler in a way, it was okay something needs cutting out . . . I will likely have a very shortened life, and I never predicted this before. I was hoping to reach at least 60.

Then I thought about what does that mean. . . . Coming into it with Parkinson's already I guess I felt some of the, some of the things that I'd thought about were applicable to the new situation in the sense of orienting myself to the here and now, and that kinda thing. . . I can't imagine what it would have been like diagnosed with cancer without having Parkinson's I can't imagine, I mean it's just, I can't imagine life with my pre-Parkinson's self having been diagnosed with cancer. It's beyond me, because after three years it had become so much a part of me and continues to be that way.

But my love of life and energy, and so on which I'm getting back now after the mutilations of cancer, unlike Parkinson's Umm, it's a catch 22 because I don't have the energy, or the physical stamina to do some of things I would normally have probably have done coming out of the cancer experience, that part of the cancer experience because of course it never goes away."
During the interview Rebecca talked about reading about cancer. At the time of her diagnosis she read breast cancer statistics. A little later she read biographical accounts, and still later she read philosophy. Currently, she is reading about what she calls the "conundrum of mortality". The one area she has not read is the "responsibility literature", for example the literature on diet and cancer.

"Actually one of the women in the group yesterday was saying she's really into this new diet and lifestyle, and all this stuff. And then, she said, 'And then I think well what if I get a reoccurrence anyway?' And I said to her, 'So that's what happens. The point is that you're changing your diet, and that's good, and that's happening right now, that's all that matters.' And that really, she felt that took a bit of a weight off, because she said, 'I really feel that if I do these things that I won't get a reoccurrence.' And it's so dangerous emotionally dangerous to say that, in my opinion. I mean women take on enough stuff without that kinda garbage. Just, ugh, makes me so annoyed."

At the end of the first interview Rebecca reflected on her experience of being diagnosed with breast cancer.

"If all goes well and so on, I'll have to at some point decide whether I want to use my experience to help others or not, umm. In terms of going back and saying, could I be of use to somebody who has young children, and if so link me up with that person. . . It worked well with Parkinson's, you know we support each other. . . And also being in the middle of it in the fall it seemed like it would never end, and now it seems like it happened in a flash. So when I think of people now my age in hospital or in those critical points, and being alone that are not knowing what's going to happen, it's sad. And I feel a certain responsibility to alleviate suffering as much as possible. I mean really what's the point of being alive."

The second interview took place one month after the first. When Rebecca first arrived we just talked for a while to get reacquainted. Then I asked Rebecca to talk about her life before
she was diagnosed with breast cancer.

Rebecca responded by saying that the major events in her life are the rites of passage for her son and the deaths of friends and family. She said that she had lost a number of friends to both AIDS and breast cancer. Also, her father had passed away the previous Christmas. Rebecca explained that it wasn’t the deaths, but her involvement in the process leading up to them, that was important. She had been involved in care, especially with her father, and "that took up a lot of my emotional time." Other than that she has had a life very much the way she wanted.

"I probably think, in a way, when you say before July I think even back to childhood in the sense of in some way being prepared for unforeseen eventualities, as much as anybody could be. So I don’t kinda crumble into little pieces. But umm, which is not to say that I haven’t gone through difficult times that way, that’s for sure. But I think in some way I, my life before July is, mostly now as well, forget those months in between, mostly now is the same way, except for some physical changes and some perceptions of living and dying, those have changed..."

I asked Rebecca to talk about these changes.

"I think that the cancer, what it represents, and what it kind of thrusts upon your mind, rather than the cancer itself, is probably the biggest influencing factor. So I would say, that the realization of our mortality is greatly emphasised because of it. The cancer itself doesn’t scare me, it’s kind of like what it is, it’s a bunch of cells, can’t do much with that.

And I think that previously, with having Parkinson’s already diagnosed that reactions had already, reactions to illness, and staging, and all those kind of things that are talked about, I had already completed that with Parkinson’s, and I just had to dredge it out again for cancer.

But the result has been, the changes have been not so much, not lifestyle except for physical limitations in terms of fatigue, and things like that, and visits to an institution that I thought I would be continuing
to go to visit other people at. And that in it's self has been a fascinating experience to go through those doors and know that you are not visiting somebody. It really is it's like, oh yeah, I've got a card and I belong here in some way.

In terms of change again I think that's the biggest one is just an emphasis on that mortality issue. And following from that I would say, a greater, for me, a greater struggle, or more energy put into, into looking at who I am and whether that's the way I really want to be. And I'm so far coming out with mostly 'yes's', but some 'no's'. And so the 'no's' I can do some work on you know in terms of change. Just for myself, not for anybody else. And that would be related to not wanting to die bitter and not wanting to die with just, without any sort of sense of peacefulness you know, that sort of thing. Those ideals that will probably never come to be."

I asked Rebecca to explain what some the "no's" are. She felt that sometimes she is a little too assertive with other people.

"But now when I feel that there is limited time I found myself looking at that, and thinking, 'Why am I doing this?' . . I would say that, that's really a profound experience for me to be able to look at my degree of tolerance, and not to say that my way's the best. Except with very very very good friends (laughter)."

Rebecca and I talked about how for some women a diagnosis of breast cancer is a major point of change in their lives, although it was not for Rebecca.

"Some people have actually have never, in my observation, have never thought about mortality at all. . . The experience has for me produced a certain amount of coercion to, to, umm. How can I explain this? You feel up against the wall. But I certainly haven't done a full sweep by any means, because my life beforehand even with the Parkinson's, and so on, was, and is a very happy. And I'm also, as I said before, of a nature as to, to evaluate things on an ongoing basis. . . I think so maybe that's a difference there in style. That has allowed me to ah, kind of incorporate it in a way umm, into a life that was already a good life.

And maybe, I'm trying to think if I were in an abusive relationship, or if I had some really big
things going on like that, I think that probably I would have changed or tried to change many many things because of this, because of the time factor. If it was a curable disease or disorder then I guess these things wouldn’t press in the way they do. . . But I find it absolutely incredible to think, I mean to me it’s the wrong time to do all that kind of stuff, because there is so much energy illness takes away. And you hear at this particular time these individuals are making these massive changes. Mine are more invisible, there are still there but it’s not like I’m changing an abode, or something like that.

The other difference with me is that with Parkinson’s I projected into the future a life of disability, in certain respects. Which would probably from diagnosis [of Parkinson’s], my diagnosis, would have set in you know probably in about five years, when the drugs become no longer effective. And so I had this sort of, in the back of my mind, this sort of image of how I was going to deal with that. I know I can deal with it but it’s not going to be pleasant. And ah, when would that mean I couldn’t work again, and so on, and so forth.

And with cancer it’s kind of rounded out the picture because that other thing still exists, but now I know I won’t be an old person with Parkinson’s who can’t do anything, and this kind of stuff. Now somebody said, well if you had a choice of one or the other which would you choose. Of course I’d choose life there’s no question. But that in terms of a life picture has changed, I mean there’s kind of an added thing there.

So the chronicity of Parkinson’s is very different from the chronicity of Cancer in that way. And one of course is visible, and one is totally invisible. And then reactions from people are very different. It’s kind of like, well if it’s not terminal in our society it seems people feel that if something’s not terminal then it’s not that serious. I mean that you can live with a chronic illness in some way, but if you’re going to die that’s just horrible, that’s just unbearable, so they say. I’ve been thinking of writing something about that sometime."

The telephone rang, interrupting the interview. It was my father, who told me my mother had just found out she had an abnormal result from a screening mammogram. After I had finished talking to my father Rebecca and I continued with the interview.
We talked about the impact of cancer on people's lives. I said doing this research "brought home that this is so much a part of so many people's lives."

"The irony being, that given that it is experienced in so many different ways. . . Again it sort of reinforces that notion of the meaning that is given to illness is really the meaning that you've given to your life, I think, over time. And if for any reason that work hasn't been done then the illness will define the person and they will have a hell of time. . .

It's like being a martyr, it kinda, it serves you in the way that you're comfortable. I mean I think about that often, that all that stuff that's brought into the picture is really what determines whether you are an ill person or a well person. . . It's very true in terms of the incidence, and so on of cancers, and yet there is such a gulf you know, between knowing of and being one of them. And I never appreciated that before until being one of them turned up. . .

So different, I mean I thought like with my friends who've died and my mother who died, all the people I have known that have died of cancer, and not of other things. And I thought that I was empathetic, which I'm sure I was but, I was trying desperately to try and understand what it would be like from their point of view. And I thought I did pretty well, but now I realize that I did abysmally. It is just so horrendously impossible. Whether one would want to do that in the first place is probably debatable. I just thought that it would help in terms of the caring part of it, but it is impossible, impossible. . ."

I asked Rebecca about her job. She said she went through her undergraduate program slowly, combining working and studying. After graduating she worked for a while and then decided to go back to university to take a graduate degree. After graduating she was hired where she has worked ever since. She enjoys her work immensely. She has been off her job since July, but went back to her workplace a few days ago to visit her co-workers.

"But I know I couldn't do it now. And whether I will ever be able to again I don't know. So, that's still up in the air. . . Maybe I have a little you know more of self-acceptance than I thought I did. It
didn’t bother me at all.

If it turns out, with my Parkinson’s progressing and so on, that I feel that work is just going to exacerbate the symptoms, and is not going to help my overall health, then I will move from short term disability to long term disability.

Then the question of meaning will come up, as it always does. So what, how am I going to participate in life and what am I going to do other than work. I don’t perceive that as a problem, it’s just gonna mean that I’m gonna have to look at myself again... The feeling I had was when I went there was basically that life goes on. Illness is part of life but it continues on basically as it has before. And umm, the work’s getting done with someone else. And everybody’s dispensable in that respect. It doesn’t have to affect perceptions of identity of self and so on."

Rebecca accepts that she may not be able to go back to work, but she has talked to other women for whom returning to work is important.

"But I know the big issue now with people that I know at, through the Cancer Agency. The big issue is am I able to go back to work. That’s a really big one. Because nobody wants to fall by the wayside."

I said some women I had interviewed had talked about returning for work after having had a diagnosis of breast cancer as being the point they felt they are back to normal. I had heard this point described as a point of closure.

"It’s funny when you mention the term closure, because well there is none really. I guess you try and, you try and mentally make it that way, but I don’t think there really ever is closure. There certainly isn’t closure for diseases like Parkinson’s I mean not at all, because it’s a day to day presence, and the cancer isn’t... I find it hard to imagine having just the cancer. I don’t know how I would be that way. I tend to think I’d leave it open to some degree. Life is different, and I don’t think I would view work as going back to what was there before, because it’s not the same as before. Things there have changed too in everybody’s workplace."

We talked about dealing with mortality.
"While you were talking I was thinking of the other very very strong element I think is, and everybody feels it, is this thrust to take control of your illness. That the younger crowd are really, I mean the younger crowd and myself included, are very vulnerable to. And I think if there's not a position taken on that it can be umm, it can be very hard to express negative, in quotes, emotions. Or to think negative things like DEATH you know, or that kind of stuff, and so it's not dealt with. . . It's kinda like don't get near me if you're going to talk about negative stuff because I'm a cancer patient and you're going to affect the growth of my cells if you sit near me, and tell me I'm gonna die. . .

I just think it's appalling. And all the therapists that say you got cancer because you're angry, and all this sort of thing. I've heard women say, they almost say that they're responsible for having got cancer because of this kinda stuff. And that's good because now they can take ownership of their illness and so on, and so forth. But I think it's very sad that that would be believed. . .

The thrust that I don't like, and I think is very, could be very damaging, umm, and is also another number that's dumped on women, which just gives it the little cream on the cake, is umm, is the sort of the focus on the cells for some reason. They focus on the cells and say, okay, now you have to spend half your day visualizing when you could be out picking strawberries or something. So the thrust is very much on those cells that went awry, and those cells are a part of your body, and so there must be a connection of what you're doing with your body, or to your body.

This is very overly simplistic as you know, but umm, but that seems to be what the focus is. Rather than umm, rather than okay going for a walk or like more mainstream stuff status quo stuff to try and gain control that way. Because nobody does really have control over their career, or their life, whether they're going to have a baby or, it's just a big myth. We have no control at all except over you know what we eat to some degree and go to the bathroom and sleep. It's very limited I think, very very limited. We don't even have control over our relationships. . . This is my own belief. And so then these people write these books think that maybe there is some control there that maybe I can get."

I asked Rebecca what she thinks caused her cancer.

"Oh, that's a simple thing to answer is just to say, 'I don't know.' I don't know, I haven't spent
that much time thinking about it. I read, you know, the various theories in terms of the immune system and all that kind of stuff, and there might be something there. There might be something there, maybe there was a, a cell from birth that, ah, or a cluster somewhere, that umm, genetically was programmed to burst open at some point with a bit of stress or something, it’s possible. But for me because it’s just possible and not provable I don’t spend much time thinking about it. And it doesn’t bother me. It’s more to me something that’s just happened that’s basically just dropped from the sky, as far as I can tell, and that’s the way it goes."

Then I asked Rebecca if she had any idea of how, or why, she got Parkinson’s

"None, none it’s total blank. I mean because, also because with cancer of course you don’t know how long it’s taken for the cells to grow to a point of being visible. And with Parkinson’s you don’t know whether maybe a mood change when you were ten was really the onset, or 20, or 30. Or there’s a stiff hand in ten years developed into a stiff leg. And I mean that’s the problem you don’t know when to start your thinking, your reflections. And given all that it just reinforces what I feel, and that is it’s just a pointless waste of energy. And I certainly don’t have a need. And if somebody said here’s a ball, a crystal ball, and look into it and I’ll tell you what caused it I still wouldn’t be interested, because the point is that it’s here, and ah. It just doesn’t interest me, it just doesn’t."

But what does interest Rebecca is the research being done on what may cause cancer.

"Well I just read about it all the time, it seems to be environmental arguments, and ah the umm, how we treat farm animals that we’re going to kill and eat, what we inject them with, and all that kind of stuff. And there’s always the immune system argument. And I mean there’s nothing to help people with the diseases deal with them, but umm, but it seems to be that one part of research that it interests me, not profoundly but, I’m not obsessed with it or anything.

To find a cause rather than treating symptoms would be a major breakthrough, umm, or in the case of cancer maybe having, developing a blood test or whatever, to determine if you’re going to be susceptible, or to what extent it’s spread, or anything like that. Those things are of interest to me and
pretty sure anyone who has carried around the sick label, I mean I can’t imagine them not being interested. Because of the potential benefit, and also if it’s not that then people behind us will benefit, and I think that that is a rather comforting thought really. . . But I don’t personalize that at all it’s just something that is in the literature, it’s just useful to read. It’s depressing to read because they haven’t made enough progress. But that’s as close as I get, but I guess I raise that because that’s as close as I get to causality.

Hopefully there are more scientists that will, that will realize that women are almost 56% of the workforce, although lowly paid, and we can’t afford to lose as many as we’re losing. So, so in that sense I don’t know what’s going to happen in ten years if it will improve or anything. Well, I sort of visualize just an up in arms type of thing. It’s really gone on too long. For breast cancer particularly."

I asked Rebecca what kind of changes she would like to see.

"Well, you know, the Forum, the Montreal Forum\textsuperscript{60} I think was a good start in the sense that well, I think that it’s sort of a slightly different, different angle in the sense of saying okay you’re the people with the disease what can."

I asked Rebecca if she had been at the Forum. She said she hadn’t but had heard it. I told her I had participated in the Forum, and she asked me some questions about the proceedings. Then she continued to talk.

"I heard it was just really intense and people with the disease were standing up and letting their voices be heard. . . That’s where the anger should be. . . There were direct questions asked about 'So, what’s being done?' ‘Why is it so slow?’ ‘How much?’ The pittance, I, I read one figure money and, ah, it was nothing, nothing. And then what’s her name the

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\textsuperscript{60} Refers to the "National Forum on Breast Cancer" held in Montreal, Quebec on November 14 to 16, 1993 (Report of the National Forum on Breast Cancer 1994). The National Forum was a meeting that brought together researchers, administrators, clinicians, and women who have had a diagnosis of breast cancer to talk about issues surrounding breast cancer.
minister said she was going to drop in another thousand dollars. Where that's going, or what they're doing with it I don't know. I mean there's anger, no question there's anger about the politics. That umm, there's no breakthrough in any kinda major way. I think markers would be a phenomenal breakthrough.

But ah, then on the closer to sea level there's an incredible anger, about the ownership of patients. Oh, that's a hot topic with me I'll tell you, it's unreal. They're kinda related in an insidious way. Kinda like keeping the sick people away from the researchers, and, and we can't let you have your records because then you'd know how serious it was, and then you'd know you might raise your voice or whatever. It's kind of an exaggeration, but it's all part of it. Instead of here's your file and ah, take it home and call me on Friday if you have any questions. But it's intense ownership, I can't believe it.

So I don't know, so I thought of that in terms of anger, but anger directed at oneself or, angry over having cancer I don't have any of that stuff. But umm, I do get angry about those other kinda control issues which I think are very legitimate. The medical establishment is umm, some people say it's slowly changing, I do not see much evidence myself. Sort of like feminism, oh it's so different now but it's really look at the wage scales it's really not that good at all."

We talked about the lack of social scientists doing research on breast cancer. Rebecca commented that, "This type of work it seems to me is what's been missing for so long. It's just not been given top rating has it?"

I asked Rebecca what she felt I should be doing with this particular research. She responded that much of the academic work has a very limited audience, and she suggested that once I have completed the academic work I should write something that would be accessible to a lay audience.

61 The Honourable Diane Marleau, Minister of Health, spoke at the opening ceremonies of the National Forum on Breast Cancer, November 14, 1993, Montreal Quebec.
After completing our discussion of research I asked Rebecca to talk about the time since she had completed treatment.

"Well I think that, since January that I’ve had to, think about, well we know about all those physical things, we know about the fatigue and all those things related to the therapy, and so on . . . But basically, one of the big things I think, for me has been how to keep my links with the outside world that’s meaningful to me. So, how do I keep my links with my friends, basically my friends . . . People were, knowing that I was sick, were, I mean, they would come over to the house and so on, and so forth, but I wasn’t able to I wasn’t able to, umm, what’s the word. It wasn’t normal, it wasn’t a normal feeling time. So I thought, so I was thinking now how can I, sort of what can I do to help this along, there wasn’t a problem or anything, but to help this along so my life resumes a certain amount of normalcy. And that people see me as who I was and not as a person with cancer . . .

I really feel that friendships are so crucial to mental health and emotional health and so on. And I value mine, but I wasn’t out there like I used to be. So, and I guess it’s an ongoing process. . . I realized that by thinking that, and by talking about it with people, that there’s a great deal of discomfort in the well part of our community about how to treat people who have finished their therapy. You probably heard this from other people, but how to treat them, umm, and to what extent you should give air time to how they feel, and what it was like, and all this kinda stuff. . . And some people deal with it by simply not umm, surfacing, not surfacing at all their uncomfortable, and so on . . .

For me it’s just important that, that I umm, take the responsibility to tell people where I’m at, and now I’m at a different place than two months ago so that means that we can go to that place, and have coffee, or what ever. And I can get back into doing some artwork and so on. And umm, I have a lot of correspondence I do just because I like to, correspond with people on paper I mean . . .

Here I am, I’m not even working, and I still feel that I’m recovering, umm, and I sound like somebody who’s a type A personality and all that sort of a thing. But at the same time it sort of felt good as well, but, but it made me sort of reflect on well I can’t grasp the whole world I mean that’s impossible. And so I think, and for me to relinquish certain things is very difficult, so if I can do one thing out of six with an individual I’ll be thrilled with that one thing.
but somebody else would say that’s not enough you’ve got to drop them, or do something you know this sort of thing."

Rebecca spends much of her time looking after her young son and playing with him. She also gardens and does other things that bring her pleasure.

"So that’s, that’s kinda new development in terms of post-treatment. . . I guess, I love doing all the things that I do and I don’t want to give anything up. So, I guess I have to view it that if it makes me feel tired then something’s wrong, maybe. That has to wait, and if not then it’s always important if I feel I’m sacrificing quiet time then also that’s not good either, health wise. So the emotional health and the physical health and the mental health kinda of all, they sort of, I probably could draw this out some how but, they each impinge on each other don’t they. So that’s part of the recent post, post time.

And I think umm, closer to January, February, March was more physical recovery and I was giving permission to myself, I think, to say okay it’s not time to go out into the outside world yet in that sense. I wasn’t isolated, but I mean, but to the degree that I’m use to. And maybe it never will be, and I probably haven’t come to terms with that yet. Because it does mean relinquishing things that I haven’t quite got my head in that space yet. . .

And I think that notion of life never standing still, trite as it sounds, does become more high profile when you get sick, when one gets sick, or at least when I got sick. Umm, that it is just that way, and things can’t be manipulated, so I found that by, by just having a certain degree of faith, and I don’t mean spiritual faith, I mean just faith, that ah, that being here in this moment in time is, there are going to be future moments and if there aren’t then that would be okay, too. It is like working towards that degree of acceptance, and internalizing it. It takes a long long time, well it’s good for anyone to do that. But that’s taken up some of my time."

I asked Rebecca to talk about her family’s reactions to her diagnosis of breast cancer. She started by saying that she and her husband, Neil, throughout their marriage have developed a pattern of communication that is open and forthright. She said
that Neil is a very sensitive male and provides her with good support.

"Although I think he feels, well he feels. He doesn’t feel happy about it, you know, because of possibly being the one that’s left as a single parent and ah, but I think the very fact that he expresses that is good, very good. But that’s not something that I can, that’s something that he kind’ve, well all those people, those partner people are alone with really. That’s their thing. But he knows that he can talk about it with me, when he wants and so on... It is hard on partnerships, very hard on partnerships."

Rebecca has encouraged her son to ask questions and to express his fears.

"Some of them are pretty pointed, like 'Is Neil going to remarry?' and 'Is he going to let me know who it’s going to be ahead of time so that I can prepare myself?’ That was a little hard.

But ah, but he also asked questions like oh, 'What is the worst kind of cancer to have?' and 'What is the best kind to have?' He said 'I thought the closer it was to your heart the worse the cancer is', so if it’s in your toe it’s a better type to have. . . Sometimes he says 'I just don’t want to talk about it anymore', which I totally respect that, that’s absolutely fine. . .

I tell him I’m here now and that’s all that matters. That’s acceptable because they don’t really think to the future."

She continued to talk about the support that she has from her family and friends.

"I really can’t think of anything negative as far as family support, and yet it’s all different. Some people lent support through action like food, you know, and other people it’s verbal, let’s go for a walk and talk about things, and other people it’s not alluding to illness at all, but just treating you like myself. You know so a strange mixture of things that way.

And friendship-wise however there were a couple of people who’ve shown such incredible discomfort about the situation that just I felt that it was too stressful for me, so I haven’t followed up with those friendships at all. And umm, I mean I just can’t deal with that... It was too hard to be around people who were, who didn’t even know they were uptight about it.
That's too hard."

Rebecca mentioned that Neil is getting a lot of support from the family and friends because of the implications of her diagnosis of cancer.

"And it's interesting with our Parkinson’s friends, because Neil hasn’t gone to the last couple of umm, support group meetings for Parkinson’s. And one of the member’s asked him he said last night why that was, that they’d missed seeing him. And he said well it’s interesting because that he knows that for me the Parkinson’s continues on as the reality. And for him the only thing that matters is the cancer, and the possible consequences of that. And so the Parkinson’s has taken on, on kind’ve a lower step. . .

Interesting because it’s not that way for me at all. So I’ve continued to go to the support group, and I certainly haven’t told him he has to go or anything, but the cancer is the big thing for him. And it is for me, but he doesn’t feel physically what it’s like to have Parkinson’s so he’s not as aware of the day to day struggles and so on and so on."

Rebecca mentioned that next week she would go to see her new oncologist. It would be her six month check up.

"Neil said that he would like to go, and what did I feel about that. I said, well I certainly don’t need you there. Not like the first appointment and so on, but he said that it was important to him to know what she was like, and so on. And it made me realize that, that point of view is as valid as my own. And that’s and he’s the one that’s going to be doing a lot of the communication probably at some point not me. . .

And yet before, before cancer the Parkinson’s affected his life and can see it still does because I can’t do certain things. . . In fact he said when we were sitting at the table he said what does it feel like for, you know, your arm to be weak like that. Oh, [I said] usually you don’t ask these kinda questions, but I guess in some way he was trying to get things back in balance in some way. And so, I told him. And so that will work out okay as long as I don’t get a number three, then we’ll really be in trouble (laughs). . . That would be asking too much. . . I don’t get any colds or flu but I just get the two big ones."
C. Conclusion

These are two rich individual stories of having a diagnosis of breast cancer. Through the use of breast cancer narratives the participants construct meaningful accounts of how the illness fits into their lives. They do this through a process of rewriting their personal biography to accommodate the breast cancer.

These stories have a very similar structure, which is shared with other participant’s stories presented in this thesis. They both begin with similar detailed account of the diagnosis and treatment of the breast cancer. These include the detection of the cancer, the actual diagnosis, details of the difficulties of treatment, and the completion of active treatment. These accounts are sub-narratives, within the larger narratives, and will be analyzed in detail in the following chapter.

Once the account of the diagnosis and treatment is completed, the remainder of the story is the creating of a meaningful life and providing a place for the cancer within that life. This is done through a process of biographical rewriting, which will be analyzed further in Chapter VII. The underlying structure is similar, but the methods that Anne and Rebecca used were different.

Anne has developed a personal account of why she may have gotten cancer. She has developed a profile of personal risk, where she describes her life prior to her diagnosis as being very stressful due to a break down of a relationship and her drinking problem. Anne then goes on to use this personal risk profile to
reevaluate her life and make changes. The change she focuses on is redeveloping a sense of self which is more meaningful.

Rebecca is unusual in that she is not interested in accounting for personal risk. She fits the cancer into a life that it was already disrupted by a diagnosis of Parkinson's. The cancer becomes meaningful by being understood as the potential end of her life. Through this construction Rebecca is rewriting her personal biography with an end, her own death. She is giving her life meaning by reconstructing her sense of time and the passage of time. Time has become more precious. Death has become a subject of contemplation rather than fear.

Anne's story also constructs a conclusion, although not as final as Rebecca's. Anne would like to "put the cancer in it's place", to be used as a resource she can draw on for inspiration and strength as she continues on with her life. This end is much more ambiguous than Rebecca's.

In both cases the participants are attempting to construct certainty throughout their story. But cancer is uncertain, it can recur at any time. Because of the nature of chronic illnesses, the majority of chronic illness narratives may include this process of revision resulting in an open-ended story, a plot with no conclusion.

Throughout their stories the participants are constantly faced with challenges to their construction of cancer. In both cases the challenges are posed by family members who have problems coping with their diagnosis of cancer. These challenges must be accounted for within the story, resulting in an account
that is being constantly revised. This will be elaborated in Chapter VIII.
Chapter VI - The Story of Diagnosis and Treatment

This chapter describes and analyzes how the participants constructed the portions of their stories dealing with their diagnosis and treatment of cancer. The structures of these portions of all the interviews are remarkably similar to these portions of Rebecca’s and Anne’s stories. They follow a simple structure, starting with the identification of something being wrong, moving through the description of the process of diagnosis and treatment, and ending with the completion of treatment and follow-up visits with their doctors. In this chapter I present the portion of the illness narrative drawn from the analysis of the common themes and structures of the individual stories of their diagnosis and treatment. With the remarkable coherence of this narrative I would say that the story of diagnosis and treatment is a sub-narrative within the larger illness narrative (Good 1994).

The description of diagnosis and treatment is the narration of the disruption in personal biography (Bury 1982, Williams 1984). After the description of the point of disruption the narrative starts the process of repair. Within these narratives the process of occurs with the reconstruction of body, self and biographical time.

The body has to be reformulated as whole after going through the ravages of treatment, as well as renegotiated as the entity in which the cancer was able to grow (Mathieson and Stam 1995).
The focus on the self is an attempt to separate the identity from the cancer, to become a person free of disease (Saillant 1990, Mathieson and Stam 1995).

Time is structured by the institutional markers of starting and completing treatment and attending follow up appointment. The passage of time is linked to the possibility of recurrence (Mathieson and Stam 1995, Comaroff and Maguire 1981).

Also, within these narratives the participants learn the discourse of hope (DelVecchio Good 1991, DelVecchio Good 1990). The discourse of hope is constructed by minimalizing the breast cancer and engaging in successful treatment, very much an institutional discourse. Through this discourse the participants construct cancer as a disease that can be survived.

Part of the similarity in the structure of the stories is a result of the women going through the experience in the specific context of the British Columbia health care system, in particular provincial health insurance and the centralized cancer treatment facilities available for women who have had a diagnosis of breast cancer in the Lower Mainland. The similarity of structure is particularly evident in the timing of events as described in the stories, such as when the women see various specialists, and the similarity in treatment protocols.

Other aspects of the similarity in these stories are the result of a shared understanding of what cancer is, and what characteristics of the disease are important. There is no doubt the women learn some of this shared understanding from participating in shared institutional and social discourses.
Other aspects come from a cultural understanding of breast cancer.

I begin by presenting three examples of stories of diagnosis and treatment. These accounts are good examples of the structure of starting with finding out something is wrong, being diagnosed, going through treatment and finishing with the completion of treatment and follow-up visits with the doctor. They also show how the participants construct the cancer as a physical entity separate from themselves, and how they deal with the physical and emotional challenges of having a diagnosis of cancer and going through treatment. Of particular interest is how the participants reconstruct time in order to incorporate institutional markers into their biography. Through these sub-narratives the participants start to use the discourse of hope.

Lynne

The first example is Lynne’s story. Lynne was 43 when she was diagnosed. She was diagnosed about eighteen months prior to the interview. She lived with her husband in a house in a newer suburb Vancouver. I interviewed Lynne a few of weeks before Christmas. We did the interview late one afternoon, after she had finished work. The interview started when I asked her when she was diagnosed and what happened.

"Ah, one day I was having a shower and I just all of a sudden felt a lump. And, so I went down to that, umm, just that open mammogram place, just a walk-in clinic. And I know when I first phoned they said that, you know, this is just for people that, you know, don’t have lumps or anything, but so I said, 'Oh, no I
don't. Because I just didn't want to go to the doctor right away, so I went there. And they did find something and then I got a call and they sent me for another mammogram to the other place where I guess they do a more thorough one, mammogram.

So I went there and then (chuckles) I guess it was really upsetting because the radiologist there said, 'Oh no, it's nothing, don't worry about it. It's a cyst.' And I said, 'Well, you know, are you sure about that?' And he says, 'Oh yeah, it's got a (unclear) around it.' So I said, 'Oh that's fine, forget about it.'

Then about a week later we had gone down to the lake and when we came back there was, umm, something on our answering machine from my doctor's office saying please come in and see us about your mammogram. So I phoned them and I said, 'Well I don't have to go it's just a cyst.' And she said, 'No, you have to come back.'

Ah, so anyway I went in and then he [her family doctor] says he wanted me to go have a needle biopsy. So he set, umm, up with a surgeon and then I had the needle biopsy and there wasn't any fluid that came out so he, the surgeon, was pretty sure it was cancer. And, but he said that he wanted to do like, umm, 'I'll go in and take out a piece and do a biopsy.'

So a week later I had that and then I went back a week later and he told me that it was cancer. So then four or five days later I went in and I had a lumpectomy."

I: "After that did you have any . . . ?"

"I had to have, umm, radiation and chemotherapy. It had spread onto some lymph nodes, I think five of the ten lymph nodes were affected. And there was also a small, umm, tumour under the arm as well, one was a lymph node. . . After I had the operation, when they took the lymph nodes out. And so then I had to have three months of chemotherapy and six weeks of radiation which I finished last December, a year ago."

I: "So you had chemotherapy?"

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62 The clinic she described is one of the clinics of the Screening Mammography Program of British Columbia. It is the policy of the Screening Mammography Program to refer any women who have symptoms back to their family doctor (King 1994, personal communication).
"I had the chemotherapy starting, I had the operation, found the lump in June, I had the operation in August, the final operation and I started my chemotherapy in September, October and November. And a week after I finished chemotherapy I started radiation for six weeks and I finished that on December 22nd, last year."

I: "How's the chemotherapy?"

"Umm, I didn't find it that hard. The first time I was sick for a couple of days but not really violently ill like, you know. The only thing that you ever hear about chemotherapy is when you see movies on cancer and you see these people where they're just up¬chucking their guts out like it's just, but I never had that reaction. I never even really threw up. I just had kind of like a liquid coming up at first, usually about eight or nine hours after I had the treatment at night and then the next day I was kind of, like tired and that, and I just lay around for a couple of days and then I was fine. You know so I never really had, and there's those anti-nausea pills they give you are really good."

I: "How about the radiation?"

"I never had any problem with the radiation either. Umm, I must have really tough skin because the girl that, I had another girl down there that lived out by this way and she didn't have a car or anything so I drove her everyday to radiation and she had a really bad reaction from it. So compared to her, that's the only person I can compare it to, I never had anything at all. It was just the last three, four days that I went, that I started to blister right underneath and then it really peeled and that. I mean that side is discoloured compared to this side, like it's a darker colour from the radiation. But that was the only, umm, thing that really happened. No I didn't have much problem at all."

Lynne said she would prefer to go to a female family doctor, but it is difficult to find a female doctor who is taking new patients in her neighbourhood.

"Like I don't have any confidence in him [her doctor], but yet who do you go to. Like, ah, not do you find a doctor that you do have confidence in, which you do, like he just seems to be just so nonchalant about everything. Like nothing really, you know, stirs him and after you've had cancer, like I mean, I mean I was the type that for forty years I never even went to
doctors hardly (laughs). I mean I’ve never been in a hospital. I’ve never been sick and I’ve never had an operation or nothing and so it wasn’t important to me then to find a good doctor. And then all of a sudden when you do have this and you find, hey, it is important to have somebody good, but, you know, it’s hard to find them."

I: "Yeah, It must be a concern."

"Yeah, I mean I just, you know, at least I have a visit to that Cancer Clinic once a year and that makes me feel a little bit better."

I: "So you go there once a year for check ups?"

"Yeah, I was going every six, well I went for six months the first year, every six months. And now she [the oncologist] said to go to my surgeon like six months and they she’ll see me the other, you know, once a year and he’ll see me once a year."

Later in the interview she talked more about her treatment and going for checkups.

"I haven’t had any difficulties, like I said it’s almost like it’s never happened. Sometimes I feel like it never happened and I guess because I never really lost my whole breast and I don’t even have a scar. Like he [the surgeon] did an excellent job. He just like took the nipple off and then took the lump out and then sewed it back on. So I mean, it’s not like I have to stare at this great big scar in the mirror everytime I undress or, like the other girl that I work with, like she’s just having a very difficult time because she had the whole breast removed and like she says, ‘Everytime I undress I cry.’"

Yeah, like to me I’ve put it all in the past and it’s, you know, when my six month check ups come up well then the day before I’m usually really (laughs) antsy pantsy because, you know, you’re, you’re thinking, ‘Oh is he going to find something?’ You know what I mean? Then you’re really nervous, you know, uptight. Yeah, or if something, like that time I woke up and my back was so sore, like, you know, then right away you think, ‘Oh, it’s going to be cancer.’"

Nancy

The second example is Nancy. Nancy was 61 when she was diagnosed. She had been diagnosed almost five years before the
interview. At the time of the interview she lived with her husband in a bungalow outside Vancouver. I did the interview on a pleasant spring afternoon. We had arranged the interview to be finished early afternoon before her husband came home from work. She started her story after I asked when had she been diagnosed with breast cancer.

"In November, umm, I went to the doctor and told him, you know, I felt there was a lump."

I: "So you found it yourself?"

"Well it was sort of strange, I didn’t really find it, actually I went to him and I said, 'Umm, is it something that you get when you glide into old age because, umm, it was right at the end of my nipple and it was like my nipple was indented. So I felt all this just happens to you when you’re getting old you’re, you know, something like that. So I just went to him and I asked him what that was and then of course he examined me and he said, 'Well the nipple is indented because there’s a lump right on the nipple and it’s making it look like it’s indented.' But I really didn’t, I sort of half expected a lump but you couldn’t really feel it, you know.

And then he sent me for a mammogram then (sighs) whenever he did that, after that I went for the biopsy. But, umm, there was something with the biopsy and it, ah, it didn’t come out too good, umm, you know the one with the needle... And so, umm, in between that time I had to go see the specialist. And then he, when the biopsy came back and he said, 'You know, they really couldn’t tell too much from it, so and they would have to operate and then find out what they got.'

I went, ah, in November, I forgot the date, a couple of weeks in November I can’t remember exactly what date it was. And I went in and he took out the lump, and just did a partial\(^{63}\) on me and then I had to wait for, I don’t know, they send it in to Vancouver or something. And like, five days or so before it, it gets sent back but they had decided when they did it that it was cancer and so they checked my lymph nodes and I had six lymph nodes infected too, so they cut them out. But they still only did the partial.

\(^{63}\) By a "partial" she is referring to a partial mastectomy. In British Columbia it is referred to as a lumpectomy.
And then I went to, they sent me to the Cancer Clinic and I had one, you one, you know, chemotherapy and then I saw the specialist there and he sort of took a look at me and he said, 'That's ridiculous,' because I had a half a boob, you know, what good is half of a boob (chuckling). He said, 'While they were doing it, seeing that it was in my lymph nodes he should have just taken the whole thing and done a radical or whatever.'

So, umm, now I went back to the surgeon and told him what the specialist at the Cancer Clinic had said and he wasn't too happy. Ah, and the doctor at the Cancer Clinic in the meantime had got in touch with him and said that I should have a radical. So I had to go back in December and take the rest of it off. And that was like a month after I went back and then they did, ah, the whole thing and then I started chemotherapy."

I: "How long were you doing chemotherapy?"

"Umm, it seemed like forever (laughs). Ah, I used to go, what was it, every third week and like it sort of seemed a long time because I was supposed to go, what was it, nine times. Every third week but a couple of times when I go in my, umm, blood count was too low so they wouldn't do it that week, so I'd have to go the following week and stuff, you know. But it was, ah, nine treatments it was and three weeks apart, sometimes it was four weeks depending on what my blood count was. . . ."

I: "Did you have many side effects with the chemo?"

"Umm, not too bad. I didn't lose all my hair. I lost quite a bit of it, mind you. I went and bought a wig before I started the chemo to get, you know, a good match. So I was wearing that for, oh, just about a month towards the end, I hadn't really, it was very thin but I hadn't gone bald or anything, you know. And, ah, oh I'd be sick for about two days after I came home or I'd come home and sleep most of the time. Actually I was usually asleep by the time I got home from the clinic with the stuff that they give you, you know."

Nancy said that after one chemotherapy treatment the nurse would not let her take the bus home, but insisted that she take a

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64 By a "radical" she is referring to a mastectomy.
taxi. Then she continued to talk about her chemotherapy treatments.

"But like I say usually it was, I’d just felt sleepy when I came home and I would take a couple of Gravol for each day, you know, for two days and sort of sleep it off. I’d throw up maybe once in awhile, you know, but after two days I’d feel okay. Except towards the end I got, umm, cold sores in my mouth, and that was painful. I couldn’t eat or drink or anything, you know, and they were painful but they, ah, prescribed some pills for them and God they must be miracle pills because with two days it was all healed up. Until I went back for my next session. You know, but apparently that is one side effect the chemo makes, umm, sort of blisters in your mouth, like some cold sores around your mouth."

A little later in the interview she said,

"I didn’t have to have radiation or anything. They just put me on those pills, Tamoxifen. They put me on those and I’m still on them. Yeah which is something. I went to the doctor on Monday as a matter of fact, I had to go get my check up, I have to go to him and get a check up and then he sends the paper to the Cancer Clinic and then they phone me and send the pills out for me. But they can’t send them until I’ve been and had my check up and they’ve got a phone call from him. So I went on Monday and had a mammogram and check up and everything on Monday and he was supposed to find out about those Tamoxifen cause I read in an article that it’s usually three years, three to five years that you’re on them so."

I: "It must be coming up to five."

"Yeah, so I was wondering how much longer I had to stay on them. . . "

I: "So do you have regular check ups with your family doctor?"

"Umm, umm every six months. I don’t go for a mammogram every six months, I just have to go for a check up from him and he fills out forms and then sends it to the Clinic."

Later in the interview Nancy talked about how her husband still worried about her. She told the story of her friend
"Like 'cause two weeks ago my girlfriend, she had a mastectomy on one side and then she went for a mammogram two weeks ago and they found another lump on the other one. So, ah, her husband and my husband, you know, he phoned of course, you know, they worry in a different way to what a woman worries, you know. So he's always, 'Have you been to the doctor? Make sure you don't miss your appointment.' And all that kind of thing.

And, ah, you know, you think oh Margaret has come up with it on the other one, what am I going to get when I go, you know."

I: "It made you a bit anxious?"

"It did on Monday when I went in for my mammogram, you know, so oh what are they gonna find. They found something on hers after all this time, are they going to do the same thing with me. So, ah, but so it's going in the back of your mind and you think, you know, I feel okay and the doctors can't feel anything but they did the same with her. They didn't feel anything she just went for a mammogram. . ."
Hospital and they said there was a tumour there and, ah, I was in the hospital practically immediately. You know, they sent me to a specialist and, ah, I was in the hospital in no time. And, ah, he at that time didn’t put me to sleep, he just went in with needles, needles I guess because it was lodged right underneath and he said he figured he could get it. And of course you’ve got to have further surgery and being let’s see I was sixty-nine, sixty-eight, no I guess I was sixty-nine, things are getting up and, ah, he just froze it and he went in and he said it was a tumour the size of a pea and it was cancer, he said. But he got it all he said and all the surrounding tissue and he was so cheerful and so fine, made me feel so good and I just really thought that was all there was to it (laughs). I come on home, I didn’t feel bad, I didn’t ache, it didn’t hurt or nothing and I just come on home.

And ah, my daughter lives in Vernon and we were out, went up to Vernon and then when I come back there was a letter stating I had to go into the Fraser Hospital. So, ah, I went back to see him, I had to go and see him, like its kind of a bit blurry then, you know, then they went into the lymph glands. And, ah, see I was in, I was in on a Sunday night. I had the surgery on Monday and I was in there until Friday. . . but anyway my lymph nodes were clear too, so, then of course, then it was down to the Cancer Clinic, you know, they didn’t really explain. I just never thought about all that.

You know it’s just, you know, ’cause we, ah, we go down to California for the winter and of course we were all scheduled to go and everything and she [the oncologist] said, ‘Well, no.’ I had to start treatment beginning in November. I had to have sixteen treatments of cobalt. So I went each day and had them done and they’re just excellent in that Cancer Clinic. . . ’cause you know you’re kind of nervous, you know, but they just make you feel so wonderful. And you didn’t always see a familiar face, it wasn’t the same person everyday, you know, but everybody was the same. And, ah, I used the cancer cars quite often because there’s quite a drive from here, you know. So, ah, I was, umm, they gave me morning appointments and I would

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66 Fraser hospital is a pseudonym.

67 Vernon is a community in the interior of British Columbia.

68 Referring to the volunteer driver program run by the Canadian Cancer Society. Volunteer drivers will pick up and take home patients undergoing treatment.
go in and I’d come back. Of course, I have to go every six months now, you know.

I can’t explain it, but I, the first time I went back after, you know, my first visit back I was very nervous, you know, going back but now it just seems like (chuckles) it’s no problems and apparently I have to go back every six months for three, well she told me three years at least, you know."

I: "So that was the first of those six month check ups you were quite nervous?"

"Yeah, very. Yeah, very. You know, when you have a little pain or something, 'Oh God, it’s coming back, it’s come back,' or something like that but, ah, and then when I came back [from California] and had to go into the, for my mammogram and my tests the next, almost like the next week. So it was, umm, I was very nervous then, you know, and, ah, I had the mammogram in the morning and then seen the doctor in the afternoon so I just stayed and, you know, in Vancouver, and ah, you always have to wait a little bit, you know (laughter) 'cause the doctor never comes in right away . . . So when she come in she said everything was fine, everything was fine (laughs) then I just kind of went to pieces, you know. But, umm, if guess then I felt well, you know, if you can kind of get through the first part of it I think the rest of it is going to be fine."

Leanne talked about what helped get through her experience with breast cancer.

"I have a lot of faith, I think that’s what, that’s what brings, you know, if you believe in that, a lot of people don’t, but I do. And I think that’s my strength, you know, to go through it but I guess. I just figured mine was very minor to what some people have had, you know. I’ve had friends that have had to have mastectomies and, ah, I just felt lucky I didn’t have to have all that."

The remainder of this chapter analyzes the stories of diagnosis and treatment. The analysis follows the chronological structure of the narratives:

A. Discovering Something is Wrong,
B. Being Diagnosed with Breast Cancer,
C. Now You Have Cancer: making decisions about treatment,
D. Going Through Treatment,
E. Stopping Treatment and Getting on with Life.

A. Discovering Something is Wrong

At the beginning of each interview the participant was asked when her breast cancer was detected and diagnosed, and then what happened next. They begin the story by talking about how they found out something was wrong. Usually this is the detection of the lump or some change in their breast, such as a dimpling of the skin or a change in the nipple. Nineteen out of 32 participants found the lump themselves. Eight participants found out something was wrong at an annual screening mammography, as in the case of Leanne.

This section of the account is usually short, highlighting the event of how the lump was detected. It is ominous in tone. For many the description of finding the lump is foreboding, it is the first sense that something is wrong.

"Yeah, at night I went to bed and I just felt my breast was actually, it was hard and this one was like jelly. And comparing them I think that something was weird. And then my nipple went in and it wouldn’t come out. And then I felt the lump. You know it kind of scared me that, at that point at three o’clock in the morning." (Virginia)

"But I knew that there was something not quite right because I had a deformity in my nipple, but I think I was fooling myself, but I knew there was something wrong. But I had hit myself with a golf club

69 Two participants indicated that the lump in their breast was found by their husbands and three indicated that the lump was found by their doctor.
in the summer of that year and then when this deformity came I kept telling myself, 'Oh, it's just from the hit and it will get better.' And then I went for my check up. My doctor was devastated when she saw what she saw and she was on the phone to the surgeon then and there." (Sarah)

For a few women the finding a change in their breast tissue was not unusual, it had happened previously. However, there is still a sense of foreboding. They describe this lump as being different and something in need of attention. In Lisa’s case she had had two previous breast biopsies. When asked if she found the lump herself she said,

"Yes, it was up here [pointing high on her breast]. And I spoke to my regular doctor about it and he said he didn’t think there was anything there to begin with but then when I kept at him about it he sent me to a breast specialist. And, ah, that’s when he put me in hospital and did the biopsy and it came out negative. And then it was, oh, a few months after that I could feel it again and I said they didn’t get all of it, you know. So I went back to the doctor, ah, the breast specialist, and he said it meant another biopsy. And they took that, and it was two weeks, I think, after that before I got notification that there was a trace of cancer."

Even at this point in the stories the lump in their breast is talked about as being cancerous, although the diagnosis is not actually known until later. Labelling the lump as cancer gives it a presence, a physical reality in the narrative. The discovery of the lump, with it’s ominous overtones, provides a sense of foreboding about what is going to come next.

B. Being Diagnosed with Breast Cancer

The next section of the story tells about the diagnosis and focuses on the actual medical procedures used in making a diagnosis. This is where the services available and the medical
practices determine the chronology of events. As well where the participants describe the point of disruption in their personal biography, the point at which the cancer is actually diagnosed. When they know something is wrong, all the participants go to see their family doctor. Then they undergo testing to determine if the lump is cancerous. The family doctor usually orders some tests, including a mammogram if they have not already had one, and refers the participant to a surgeon. The surgeon usually does some form of biopsy to get a sample of cells from the lump. The sample of the tissue is sent to a pathologist to determine if the tumour is cancerous. If the biopsy is indeterminate then further testing may be necessary, including a more extensive biopsy.

What is emphasized in this section of the story is how quickly events happened. Time, which is related to the growth of the cancer, is one of the characteristics important in constructing the meaning of breast cancer. Within the story the participants emphasize that once they became aware something was wrong they quickly brought their concerns to the attention of their doctor. Then the story continues about how quickly their doctor responded to their concerns.

70 In British Columbia under the provincial medical insurance plan it is necessary for women to see a general practitioner, usually a family doctor, before being referred to a specialist.

71 A biopsy is the removal of cells or tissue. This tissue is examined by a pathologist to determine if the tumour is cancerous. There are a number of different types of biopsies. Some biopsies take only a few cells, some take a piece of the lump and others remove the lump completely (Olivotto, Gelmon and Kuusk 1995).
"And, ah, when I discovered the lump I went to my doctor... our family doctor and, umm, he immediately set up an appointment with an x-ray specialist which I went to and I was very fortunate because everything fell into place very quickly. And then I went back to him after that was taken and the x-ray technician report said, umm, he didn't think it was cancer, but if it was his wife he would suggest she follow through.

But actually the family doctor he, when he got the results back he decided he would, to make certain, he would send me to a surgeon. Which, umm, it was about two weeks, I was supposed to go to him but there again they had a cancellation so I got there within one week.

As I say, everything sort of fell into place and, ah, then from there she (the surgeon) had set up an appointment the following week. I went up to the hospital and I had the test there in the hospital. I went in for day surgery, I had the lump removed, I came home and the following week I went back and had two lymph nodes removed." (Laura)

"How did it happen? I saw a dimpling on the lower part of my breast so contacted my G.P. who immediately referred me to Dr. Matthews\(^{72}\), umm, and then I was sent to the Cancer Agency where they did a biopsy, and it was all done very quickly. It was all done, I would think if my memory serves me correctly within, within a week. Dr. Matthews was leaving on holidays and, umm, wanted to look after [it] immediately. I, there was no waiting period, there was no psychological upset due to sitting about and worrying about it." (Eileen)

Any referrals also happened quickly, within two weeks of their originally contacting their family doctor. Only a few women delayed going to see the family doctor after discovering something was wrong. Andrea's story is,

"Oh I was just, umm, sitting here talking to a girl across the table at work and I was sort of going like this [fingering the neckline of her sweater], you know, while listening to her talk and, umm, that's when I found it..."

I: "Yeah, so what happened then?"

"Well, I just had phoned the doctor to make an appointment with him and then in the meantime he was in

\(^{72}\) Dr. Matthews is a pseudonym.
England on holidays and he had a replacement doctor. So what I did was I phoned back and I said to his secretary, 'I think I'll wait until the doctor comes home to make an appointment.' So I wasn't even thinking anything was wrong with me. Nothing happens to you, it happens to everybody else. So, ah, I phoned then when the doctor was back so I went in and I just says to him, 'You know, I found a lump the other day.' And he was the one that just about fell off the chair. 'What's the hurry, you know, I just found a lump.' So within a couple of minutes he had an appointment with the other doctor."

There were three stories where the participant described how their doctor delayed for some reason. In each case, after the initial delay, the participant chose to see another doctor. Susan told such a story.

"I had seen another doctor and, umm, he sent me for a routine mammogram. I was a little disappointed with him because he never did get back to me. I had to contact him. And then I went in and he did a needle biopsy in his office. And he sent me to the hospital with the bottle and I didn't just drop it I waited. And she [the lab technician] says, 'Will you put your name on the bottle.' The doctor didn't even put it on the bottle. So I decided to change doctors. And a friend of mine knew Dr. Cameron as a patient and she got me into see her. And then she sent me right away to see Dr. North because he had an opening, and I think it was about three weeks before I got to see him. And he asked me, you know, if I wanted to have the pathologist right there and they do everything [both the biopsy and auxiliary dissection], or just go, you know, as a day patient. And I said I'd rather have it over and done with at once. And, umm, he said only one lymph node was affected."

A recurring theme at this point in the story is how quickly things happened, that very little time was allowed to pass between their finding out something was wrong and getting a diagnosis and starting treatment. The participants emphasize

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73 Dr. Cameron is a pseudonym.

74 Dr. North is a pseudonym.
that the less time that has passed the better. Even in those stories where a delay occurred action was taken to counter the delay and speed up the process of diagnosis and treatment. There is an urgency to deal with the cancer, to have it removed and treated.

The implication is that if the cancer was left unattended it will become worse, it will spread to other areas in the body and the prognosis will be worse. Therefore in order to construct a story with the best prognosis possible it is important that as little time pass between finding out that something is wrong and starting treatment. Constructing time in this way, passing quickly to minimize the cancer's growth, raises the possibility that the cancer will be successfully treated, eliminating uncertainty and creating hope for the future.

Later in the interviews the participants continue the talk about the link between the passage of time and the seriousness of the cancer. When talking about the diagnosis of breast cancer generally, a few women made the point that it is not very serious if it is caught in time "... that they catch it early, that's the most important thing." When talking about the number of women who die from breast cancer each year Leslie said,

"Yeah, but that's the ones that don't look after it in time. I'm sure it is, they've let it go and let it go. Like I say the ones that are afraid to find out about themselves, they let it go and let it go and after a while its too late and they want help and they can only help so far and that's it."

The process of diagnosis culminates with the participant being told she has breast cancer. This is the point of disruption. Some participants actually describe how they were
told and talk about their reactions to being diagnosed. Their reactions are very personal and occasionally very disturbing, for example Trisha’s story.

"Well oddly enough I guess, it is my naivete again, but I really did not think I had cancer. I didn’t even entertain the possibility that it might be cancer. Oddly enough when I have, when you have a lump you think you would think about it, but I just put it out of my mind. Oh, it’s a cyst, I know my mother had a cyst. It must be something like that. So I was not prepared for him to come and tell me I have cancer."

The day of her first surgery Trisha had arranged for her husband to come and pick her up from the hospital. Her husband was coming at five o’clock. As Trisha was recovering the nurse told her that the surgeon was coming to see her.

"It never occurred to me that he’d be coming to tell me the results of the biopsy. I just didn’t even, I didn’t realize he’d know that soon. . . I was in a little cubicle, not in a real room, it was like a ward and there were curtains pulled across. So, I was in there laying in a bed, just recovering. And I felt alright, but I hadn’t been awake for that long. And my husband was due to arrive in the next half hour. And the surgeon walked in. And he, he just sat down and said, 'You have, the lump was cancerous, you have breast cancer.'

I was just in shock, I couldn’t believe he told me that. And he told me then what would happen next, that I’d have to have more surgery, and then I would have to have radiation. And he said that, that would be in Vancouver, and you’d probably have to take some time off work. . .

I wasn’t prepared for it at all, I was astounded. And my initial reaction was to say, 'Yeah, okay, okay.' That’s what I did. Then he left. And there I was in this little cubicle all by myself, I didn’t know anybody, and I waited half an hour for my husband to come. And that was one of the worst experiences in my whole life. I didn’t know what to do and I didn’t have anybody to talk to. . . I just felt so alone. And I felt, I was thunderstruck. And I was crying, I remember that, I was crying and I was in shock. And I wanted desperately for my husband to be there.

I really resented that fact that I could have
phoned him. . . He could have been with me for that news, so easily. And I guess partly, that would be my fault. I just wish he could have prepared me for that, I wish he had said, 'Do you want someone to be there with you?'

It was a bad evening too. My husband arrived about half an hour later. And I told him. And I just cried on his shoulder. He hugged me. And then we went home. And then it was shock. That, that was tough to deal with. But then you just know you just have to, you just have to deal with that, and that's fine. You just have to, the way I started feeling was you have to go through with it now, you know. I have come this far with it, and I've got to get it out."

For many participants being told they have cancer is traumatic. It brings a flood of emotions and fears about the future. Part of the story of diagnosis is talking about those fears and how the participants had to overcome their emotions in order to continue on and to deal with the upcoming treatments.

"Well, I had a good cry. I had a really good cry. I had only just, this was my first visit to my new G.P., Dr. April and, ah, so I had a real good cry when he phoned me. Umm, and I, I remember saying to him, 'Oh dear me, I wish, wish I knew you better. I wish I could talk to you about this.' However, ah, that was it, it [the diagnosis and start of treatment] was done very quickly. So I think that was excellent. I feel very sorry for people who have to sit around and wait. And to give you an example of that, my husband is waiting right now for bypass surgery and I feel very sorry for him because he has no date." (Eileen)

"It's really hard to because, umm, I remember when the surgeon told me I had, he held my hand and he told me it was cancerous. I says, 'I don't like to hear that word.' He says, 'Nobody likes to hear that word.' But what are you going to do, I mean I had to go out there with it and that was it. And that's what made me tough and strong, getting over top of it. Em, Em. I think what you must do you must do and do the best you can with it and stay on top, you know." (Leslie)

75 Dr. April is a pseudonym.
In some cases the participants described having minimal adverse reaction when they were first told they have cancer; it is almost like they are holding something back. They stress that the most important thing at this time is dealing with the cancer, getting rid of the cancer.

"Umm, they did the biopsy and he [the surgeon] took a couple of pieces of frozen tissue and sent it to the lab. Well, by that time I was back to the ward [where she worked]. Ah, he came in that evening, he wasn't very happy I could tell by the look on his face. He just handed me the lab report. I read the lab report. He handed me the O.R. sheet [surgical consent], I signed it, and the next day I went up to the O.R. That was it."

I: "So you were expecting something like that?"

"No."

I: "No. How did you feel when that hit you?"

"Cancer, get rid of it. I mean as you can see [from her home] I'm very, well I'm religious in my own way. Ah, and it says there that Jesus Christ said if your eye is bad, take it out, throw it away. If your arm is bad take it off, throw it away. That's the same thing, that's the way I feel." (Sandra)

Being diagnosed with breast cancer is the major point of disruption in the narratives. It is the first of many challenges to self and identity. Cancer is seen as a "death sentence", a threat to life. At the point of diagnosis the fear of dying becomes a reality and a predominant feature in the story.

However, being diagnosed with breast cancer raises other fears. It raises the fear of treatment. The participants are afraid of losing their breasts and having to go through treatment, in particular chemotherapy. This leads into the next part of the story, which is deciding what treatments to have and actually going through them.
C. Now You Have Cancer: making decisions about treatment

Once the participants find out they have cancer they talk about making decisions about their treatment. Treatments are recommended after an assessment by an oncologist, based on part on the characteristics of the tumour. In all cases this assessment was done by oncologists at the Vancouver Clinic of the British Columbia Cancer Agency.

I have divided the treatments into two phases. The first is the surgical removal of the tumour, usually done by the surgeon to whom the participants have been referred by their family doctor. The second phase is the treatments which usually occur after the surgery\textsuperscript{76}. These can include radiation therapy, chemotherapy and hormonal therapy.

1. Surgery

Most of the participants have a biopsy at the time of diagnosis. Having the results of the biopsy, the surgeon recommends either a lumpectomy or a mastectomy, if the tumour was not completely removed with the biopsy\textsuperscript{77}. The surgeon's recommendations depend on the size and location of the tumour in

\textsuperscript{76} There were three participants who had chemotherapy and radiation therapy prior to surgery. This is most commonly done to decrease the size of the tumour before surgical removal (Olivotto, Gelmon and Kuusk 1995).

\textsuperscript{77} There was only one woman who told the story that she did not know going into the surgery whether or not she was going to lose her breast. She probably had a one-step procedure. In the interviews done with women in 1987 (Mears, 1988), who had their surgery in 1980 and 1981 majority had a one-step procedure.
the breast. At this point the participant must make a decision about what type of surgery to have.

At this stage of the story it is critically important that the tumour is completely removed from their body. Earlier in the story the participants constructed the cancer as a physical entity. Now the surgery is described as the physical removal of the cancer from their body. A common statement is "... they got it all." The body has failed by allowing the cancer to grow (Mathieson and Stam 1995), and therefore it is important to remove the cancer from the body in order to allow for the start of a repair process.

Almost as critical to the story is how this removal is done. When first diagnosed with cancer all the participants are faced with the fear of having to have a mastectomy.

"My grandmother had breast cancer but that was when they did what I call strip mining, you know, they basically grabbed a, a piece of her flesh and went rip and what you had left was bones underneath, you know, those kind of days. So of course, I had to deal with that, you know, I'd lay in bed and look down and I'd start to cry 'cause I'd think well all I'm going to see is these bones sticking out, you know." (Julie)

When many of the participants are first diagnosed with breast cancer a mastectomy is perceived as the only option available to them. This is the case in the lay literature as

78 Over the past decade there has been an increase in the use of lumpectomies, or breast conserving surgery, in the surgical treatment of breast cancer in the province of British Columbia (Kuusk, 1994 personal communication).

79 Julie is describing a Halsted radical mastectomy where the breast and the muscles of the chest wall were removed. Currently this procedure is only done in cases where the tumour has invaded the chest wall (Kuusk, personal communication). In the past this procedure was common treatment of breast cancer.
well (Rollin 1976, Crowie 1994). The idea of the mutilation of having their breast amputated is horrifying.

Those participants for whom a lumpectomy is the recommended surgery express relief at not having to have a mastectomy.

"And you don’t have to have an instant mastectomy, like that was, when I first had the diagnosis like I didn’t know very much about techniques and things. And my mother had a double mastectomy and chemo, but I found out later that’s ‘cause she was fairly advanced and my first fear was, ‘Oh no, my breast will get hacked off or something,’ but it wasn’t. It was a great relief to have that option of making a segmental incision plus radiation. Because my surgeon explained to me oh, in the long term that has the same overall effect as, umm, as a mastectomy so that was the first big relief, you know." (Amy)

"So I did go back later on the Wednesday afternoon and it was confirmed, he said, ‘They were ninety percent sure that it was (pause) carcinoma.’ But in order to be a hundred percent sure he wanted to do a cut down biopsy. And then there was the long weekend so next Wednesday I had the cut down done. And the next day I was admitted and then the next day I had surgery. And originally he told me that I had a choice of a radical or a lumpectomy and have my nodes removed. And he said because of the size of it he said that I was better off having a lumpectomy which is what I opted for." (Jennifer)

For those who do go through with the mastectomy, getting used to their "new" body is traumatic. The worst point in the process is looking at the surgical wound for the first time. But the trauma does not end there.

"But, ah, I was never that much for modesty I guess, its really, at the beginning, you know, to lose your breast, it is, ah, a trauma you know. Sometimes, sometimes it’s not too bad and other days it, it hits you funny, you know, you can’t pinpoint it, you just feel that something’s different. But I seemed to somehow come through it, some days you wonder, you know." (Virginia)

80 Segmental incision is a form of lumpectomy (Love, 1990).
Most of the participants agree with the recommendations of their surgeons. For example Susan started off wanting to have a mastectomy, but eventually settled on having a lumpectomy. She explained why she wanted to have the mastectomy.

"... In fact I think my surgeon was kind of shocked 'cause I told him if it was cancer I wanted him to take the breast off right now and get it over with. Well, he says, 'It's high up.' He says, 'I don't think we'll have to take it off.' I says, 'Well if you have to, do. I don't want any monkeying around, I want it over and done with, I don't want in a year to come back and have surgery again.' I think he was a bit shocked."

I: "What would shock him about that, what do you think?"

"You know, umm, in my opinion men have put too much stock in a woman's bust, you know (laughs), and, ah, I think that's why he was a little bit shocked, that most of his patients probably had a reaction to the thought of losing their bust."

However, Susan eventually accepted her doctor's recommendation and had a lumpectomy and radiation. Later in the interview she said, "I've heard of some of the people that, you know, have had breast cancer and then they only did a lumpectomy and they, they've been fine for years." For Susan the main consideration in making her decision about her treatment was which would provide her with the best prognosis.

Eileen's surgeon did not offer her a lumpectomy, and she was happy having a mastectomy, for her it was the appropriate treatment. During the interview Eileen talked about her father, who had been diagnosed with cancer and refused surgery.

"I was with him when he died, now, umm, I don't know whether that gave me strength the fact that he refused surgery, ah, I don't know if anyone would interpret that as giving me strength, umm, I know I would not have refused surgery, okay, I know that some people have been, it wasn't an option to me, they
didn’t say have, umm, it when they just do a . . ."

I: "A lumpectomy?"

"A lumpectomy. They, that wasn’t offered to me so I don’t know if I had been given the option, I can’t say what my, I think my choice would have been the way it was done. If I had been offered a lumpectomy I think I would have said, ‘No.’ Because I see, I see people, umm, well, okay, I think its my friend whose having the psychological problems, she had a lumpectomy."

There were cases of participants requesting, and having, a mastectomy after the surgeon recommended a lumpectomy. Denise explained why she made the choice she did.

"Then is was a case of waiting to get back to the surgeon to discuss options. So again, let’s wait for an appointment, then he gave me my options and my choice was to have a modified mastectomy, modified radical. Basically because it was lobular [type of cancer], because of my age, cause my kids didn’t have a dad around [recent divorce] and my beau . . ."

I: "When you were making the decision to have the mastectomy what alternatives did the surgeon present?"

"Lumpectomy. Umm, simple mastectomy, modified radical, he explained to me they don’t do radicals anymore. Umm, and if I chose the lumpectomy then you didn’t have the option you had to go lumpectomy and radiation or. Or whatever, and you know my thing was get rid of it, get rid of, who wants half a breast. Right. And it was very fortunate because after I had the mastectomy they found four other lumps in the breast. Ah, ah, So that makes me really happy because I have a girlfriend that opted for a lumpectomy and she’s now dead."

Like Susan and Eileen, Denise talked about how the decision she made about her surgical treatment was a good decision for her. With the possibility of cancer elsewhere in the breast and with her friend’s experience, the choice of a mastectomy may have extended her life, given her a better chance of surviving her diagnosis of breast cancer.
These three examples demonstrate how the participants evaluate the appropriateness of surgical treatment in their particular case. Most of the evaluations are implicit, in that they do not question the type of surgery they had. Others are more explicit, as when Susan, Denise and Eileen, compare their experience favourably to that of others.

Not all the evaluations are positive. Julie talked about how she would have liked to have known about reconstructive surgery before she had her mastectomy. Julie had her chemotherapy and radiation treatment before surgery, to try to reduce the size of the tumour so she would have the option of a lumpectomy. However, the treatment was not as successful as hoped and she had to have a mastectomy anyway.

"Umm, that's one thing that I wish I had known. The minute I had been told I had breast cancer I wish I had all that information, I wish I had been shown the pictures of the before and after. I wish I knew the stats of how often it will work, how often it won't. I wish I had all that in my little brain then, because then, sitting in chemo it would have been a big smile on my face, it would have been so much better. I probably would have just said forget the chemo and radiation and I'll go for the mastectomy and cut out all those costs and all the effort for me and my family and work and that and just gone straight to the surgery."

In constructing the story of treatment the participants tend to construct their treatment as having got all the cancer, removed it from their bodies, and as being the appropriate treatment for them. There are notable exceptions, like Trisha (see below), who questioned the appropriateness of her treatment. The main trend however is to present the treatment as successful. This provides hope that the cancer will not recur. This is part
of the construction of a discourse of hope developed within the breast cancer narratives.

2. Other Treatments

The next stage in the story is making decisions about secondary treatment. The oncologists make recommendations for treatment based on the physical characteristics of the tumour. It is interesting which of the physical characteristics of the tumour the participants remembered and included in their story. Most participants did not know, or did not include in their story, the type of cancer they had. Only three participants, including Anne, could tell me the type of cancer they had.

However, there are two characteristics of the tumour that are commonly included in the story: the size of the tumour and the degree of lymph node involvement. Both these characteristics are used to stage the tumour (See Chapter IV) and assist in the determination of the type of treatment. In the participants' stories the size of the tumour and the number of lymph nodes are used as markers of the severity of the cancer.

The size of the tumour is consistently mentioned in the story of diagnosis and treatment. In some cases the participant could tell its exact size, like Anne. Others only described it as small, "the size of a pea" or a "trace". There were only two participants who said the tumour was quite large. One described

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81 It is interesting to note that in interviews done in 1987 with women who had had a diagnosis of breast cancer (Mears 1988) many women included a third characteristic the estrogen receptor status of the tumour.
the tumour being "quite massive".

There is an understanding that the smaller the tumour is when it is detected the better that is. Most of the participants talked about how important it was that their cancer was small when it was detected. One participant said if she had not had a mammogram by the time the tumour was large enough for her to find herself it would have been a "little more serious".

"Like for instance in my case I never felt no lump, no nothing, no sickness, no nothing whatsoever. And then in the mammogram, if it was not in the mammogram I would have never known nothing. This point, and another thing is that in the mammogram was showing where the tumour was, the tiny, tiny tumour, my family doctor couldn't find it. Even though it was showing in the mammogram he couldn't find it on me... because I mean if, what would happen if I would have waited. Maybe I wouldn't have a hope or nothing." (Allison)

"Ah, just comes I guess and that's, and that's it. And thank goodness for the mammograms really because, ah, I think, ah, I had asked her at the clinic, when she was examining me, and she said she thought maybe it would have taken about three years for that to surface to a lump." (Leanne)

If the tumour is small it is assumed there is less chance the cancer has spread to other parts of the body. Those who indicated their cancer was larger expressed concern their cancer might be worse than if it had been detected earlier. Knowing the tumour is small is very reassuring. For example, having the tumour detected by mammography when it was too small to be felt by physical examination is an advantage. If the tumour is small the chances of successful treatment are better, and the chances of surviving the cancer are better. The construction of a small tumour, detected early, is another element in the discourse on hope for the future.
The second characteristic of the tumour the majority of the participants talked about was the number of lymph nodes involved. It is at the time of the surgery that an axillary lymph node dissection is done. The lymph nodes are used to indicate whether the cancer has spread to the blood stream and to decide about appropriate treatment (see Chapter IV).

When they mentioned lymph nodes the participants stressed that they did not have many, if any, involved. Jennifer, who was quoted in the previous section, was very glad that she did not have to have a mastectomy. When talking about her lymph nodes she said,

"I recovered really well from that [the surgery] and, ah, got the results of my lymph nodes and they were negative which made me really happy."

The reason that Jennifer, and others, were so happy is that with no lymph node involvement there is less chance the cancer has spread. If the cancer has not spread it is not only not as serious, but there is less chance they will have to have chemotherapy.

Even in cases were there were a larger number of lymph nodes involved the participants tended to minimize the seriousness of their cancer. Jill had ten out of thirteen lymph nodes involved. Talking to her surgeon she asked,

"Does that necessarily mean that, that it may come back? And she [the surgeon] said, 'Not necessarily, and if it does we have other tricks up our sleeve.' (laughter) And I said to myself, 'I don’t know if I’m going to submit to that (laughter).’ But it’s so far

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82 An axillary lymph node dissection is the surgical removal of lymph nodes from the armpit area (Love 1990). The lymph nodes under the arm are an area to which the cancer may spread (Olivotto, Gelmon and Kuusk 1995).
so good . . . They haven't heard of anything else coming back and I choose to think that they have taken care of it and it's, I think of it as something past."

Talking about the cancer as a tumour, that has physical characteristics, creates a physical presence. It makes the cancer real, in the sense of creating an object. Gordon (1990) also found this idea of creating the cancer as an object or an "other". If the cancer is constructed as a physical presence then it can be successfully removed and treated. When the cancer is surgically removed the description of getting all the cancer, getting rid of it, becomes meaningful.

In describing the tumour itself the participants talked about how the tumour was small, how it was detected early and then taken care of quickly before it had a chance to spread. The story becomes one in which the cancer was not that serious when it was found and is now gone.

By describing the cancer as not being "that bad" the women minimize it. In a way, this is actually the case according to the biomedical statistics of survival (see Chapter IV). All 29 participants in the shorter interviews did have a good medical prognosis. They were either stage I or II (see Chapter IV). However, the process of minimizing the cancer is also a way of creating a discourse of hope about the future. Hope that their cancer will not return. Hope that their cancer will not kill them.

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83 I do not know Anne, Trisha or Rebecca's prognosis.
D. Going through Treatment

"And I found the radiation exhausting. I guess because I'd never had a chance to really recover from the surgery, you know, it was just one thing after another. And I really, well, emotionally until halfway through my radiation and all of a sudden my emotions broke... So I think I cried for about a week and then I got over that but I think there's just, I finally realized what I was going through." (Jennifer)

Once surgery has been completed and a decision made that further treatment is required\(^{84}\) the treatments are started. The treatments may include one or more of radiation therapy\(^{85}\), chemotherapy\(^{86}\) and hormonal therapy\(^{87}\).

For some participants, like Jennifer, the start of treatment is the point in their story where they talk about coming to terms with the fact they have cancer. The treatments are very difficult, both physically and emotionally. Part of the process of coming to terms with the cancer is coming to terms with the challenges to self, identity and body.

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\(^{84}\) There were three participants who had radiation and chemotherapy prior to their surgery.

\(^{85}\) At the time of the interviews the Vancouver Clinic of the British Columbia Cancer Agency was the only facility providing radiation therapy for women living in the Lower Mainland. Radiation was usually 15 consecutive working days of treatment.

\(^{86}\) Chemotherapy is the use of cytotoxic drugs used in the treatment of breast cancer. These drugs prevent cell division which causes the cells to die. When given they act on all rapidly dividing cells including hair cells, bone marrow cells and cancer cells (Love 1990). Chemotherapy can be administered at the Vancouver Clinic or at a number of other hospitals in the Lower Mainland.

\(^{87}\) Hormonal therapy is the manipulation of hormones in the body to prevent the growth of malignant cells that depend on estrogen. In this study the women taking hormonal therapy were taking tamoxifen. Tamoxifen is an estrogen blocking drug. Tamoxifen is taken for three to five years after other treatments have finished (Love 1990).
In the story of diagnosis and treatment the talk about the treatment process includes two themes. The first is the description of the treatment, its side effects and how the woman manages to get through the process. The second theme is an evaluation of this process.

1. Talking about Treatment

Listening to descriptions of the treatment and the side effects the participants had to cope with, it was difficult for me to comprehend the nature of their suffering. This was especially the case for women who endured chemotherapy. It was interesting that the telling of the difficulty, and in some cases almost making light of difficulty, is an important part of the story.

Not all the participants had to have further treatment. Three participants who had mastectomies did not require anything further. Two others who had mastectomies had only hormonal treatment. All the rest had at least radiation or chemotherapy, and some had hormonal therapy as well. Those who did not have treatment described their breast cancer as being not that "... horrendous an experience, because I didn't have to have chemotherapy."

Twenty-two of the 32 participants had radiation therapy. Nine of these had radiation on its own, or in combination with hormonal therapy like Leanne. In terms of side effects, having radiation therapy on its own is easier than in combination with chemotherapy or chemotherapy on its own, however there are still
problems.

The side effect the women mentioned most commonly was fatigue. Fatigue is caused not only by the radiation itself, but also by the intensity of the treatment. The participants became fatigued going for treatment 15 to 16 days in a row. With the only radiation treatment facility being in the city of Vancouver, a number of the participants had to travel more than an hour each way to get to the clinic. In some cases the fatigue lasted well beyond the completion of treatment. Andrea, who had only radiation therapy, told me,

"Yeah, and I was very, very tired after radiation, like I guess, it did slow me down 'cause I've put weight on and, you know, 'cause I was only about a hundred and ten pounds, and I've put weight on because doing my housework I did it slow, and when I went back to work, like my work was slow and things like that. And even my son, like he says to me, 'You're tired, you're always tired.' And I just said to him, 'Well, it's just, I'm just tired that's all.'"

There are other problems the women talked about related to going through radiation, such as problems with skin reactions, mild burns and rashes, and throat problems. Another problem is a hot or burning sensation in the area that had been irradiated, which lasts for a time after treatment had stopped. Andrea experienced this as well,

"And then, ah, radiation. I had seventeen and then my last two, like on the sixteenth day I had a booster along with my regular one, on the seventeenth day I had a booster along with my regular one. Then for two years I just about died from heat, from the radiation, oh yeah, it was terrible. I was hot, I was hot all the time."

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88 Leanne's story is a little unusual in that she did not mention having any side effects.
Going through chemotherapy is extremely difficult. Sixteen of the 32 participants had chemotherapy. Most of their experiences were quite similar to Anne’s, set out above. Most of the participants had chemotherapy injected directly into their bloodstream, there was only one who had some of her drugs in pill form. The length of the treatment varied depending on the dosage required. Some of the participants were also given a choice of whether they wanted to have a shorter or longer course of treatment. Many chose the shorter course to get the treatment "over with sooner" even though they knew their reactions would be more severe.

"I had four injections every three weeks. So I finished just before Thanksgiving, 'cause I remember I was invited for Thanksgiving dinner and I said 'No, I'm sorry I can't make it.' 'cause it was the last and of course each one gets worse. The first one really didn't bother me much except I was a bit anorexic. The second one made me feel quite a bit more ill and my vein went sort of into spasm. And the third one, when I was supposed to go for the third one I really didn't want to go. I just didn't want to go, but I knew I had to, and my friends coaxed me. And then the fourth one I knew it was the last one. Yeah I knew that was it and, ah, just want it over and done with to get on with my life."

The most striking thing about descriptions of chemotherapy is just how sick the women get. Up until this point, except for the surgery, the women are usually quite well. With the start of chemotherapy they become seriously ill. Some of the symptoms the women have to deal with are severe nausea, loss of hair,

89 Compared to the earlier interviews done in 1987 (Mears 1988) the use of anti-nausea medications have made coping with the nausea and vomiting of the chemotherapy easier for some women. The other main difference between the two groups is that the chemotherapy protocols have become shorter.
including eyebrows, eyelashes and pubic hair, and sores on the mouth and gums, as described in Chapter V and at the beginning of this chapter.

Another striking feature in the description of chemotherapy is how the treatments get progressively worse. For those ten participants who had radiation after chemotherapy the radiation seemed to be worse as well.

"Well at first I, ah, I kind of thought that it would be interesting to go through it, you know, I just didn’t really think it was going to be as bad as it was. And, umm, the chemo treatments got worse as they went along. The first time I, ah, I thought I was going to, I was, I wasn’t that sick. And then towards the end I’d be throwing up fifteen times and, ah, radiation the same. It started sort of not so bad and then at the end, by the end of the radiation treatments it would be quite, ah, I had burnt skin. . . Yeah, like ’cause I had some burns. Yeah very, very, umm, rough skin, it hurt a bit. It wasn’t as bad as chemotherapy at all, and I didn’t enjoy losing my hair. That was awful." (Angela)

There are other, less common, side effects of chemotherapy. For example, Stephanie had chemotherapy-induced menopause and had to deal with both the side effects of chemotherapy and symptoms of menopause. She told how she would constantly break out in a sweat from head to foot. It was a very hot summer and the menopause symptoms just made the heat more difficult to bear.

Chemotherapy also lowers the patient’s white blood cell count, and many of the participants mentioned that chemotherapy treatments had to be delayed because their white blood cell counts were too low. In some cases this extended the course of

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90 Trisha’s case of having chemotherapy after radiation was unusual in all the other cases radiation was after, or in one case in the middle, of the chemotherapy.
the treatment. Lowering the white blood cell count can result in usually minor infections becoming very serious, as in the case described by Trisha in the next section.

Eight participants had hormonal therapy. The therapy prescribed was the drug Tamoxifen\textsuperscript{91}. Tamoxifen is taken over a long period. Some participants took it for from one to five years. Compared to other treatments the participants identify very few side effects strictly related to tamoxifen\textsuperscript{92}. Sarah and Virginia both said they had gained weight as a result of the use of tamoxifen, which they found to be very frustrating. However, the tamoxifen does help to prevent a recurrence. As Jill expressed it "... the tamoxifen which I take keeps everything under control."

The participants have an interesting interpretation of the side effects of the treatments. The side effects are a tangible measure of the impact the treatment was having on the body and therefore on the cancer. It is comforting to know that something was being done, and useful in trying to face the next treatment.

Going through treatment for breast cancer is extremely difficult and brings home the reality of exactly what is happening. Those participants who did not have to have treatment acknowledged their experience was not as bad.

\textsuperscript{91} Tamoxifen is an estrogen blocking drug and is used to block the growth-stimulating effects of estrogen on cancer cells (Olivotto, Gelmon and Kuusk 1995).

\textsuperscript{92} There have been some serious side effects with Tamoxifen, although none of the participants mentioned any.
Coping with the side effects of treatment is extremely difficult. The participants developed strategies for getting through. Some participants took time off work while going through treatment. Some stressed the importance of having friends or family who could take them to appointments and help them throughout treatment. Some joined support groups and others shared their experiences with other women who had had a diagnosis of breast cancer. Some just tried to keep their lives as normal as possible.

"You really want normalcy in your life, you really do 'cause that sort of makes you feel like you're not giving into your illness. . . You've got a fighting chance against it." (Amy)

Treatment is insurance for "getting it all." The surgical removal of the tumour removes the cancer from their body, but there is still the concern that it may have spread. Cancer spreads when cancer cells move to other areas of the body. The participants are told by the treatment staff the treatment is a way of getting rid of, or killing, any stray cells which might be still present in the body. This is why, despite the serious and debilitating side effects, the participants elect to continue with treatment. The treatment is the way to eliminate the cancer and improve their chance of survival.

"I'm just wondering, 'Oh, it's going to come back. Did they get it all?' 'cause they said that's why I had to take these treatments and the chemotherapy and the radiation, 'cause they said they weren't sure if they got it." (Virginia)

"Yeah and I think it's from all the treatment. When you figure they're shooting all that poison into your system and trying to kill the cancer cells, they do a lot of damage, trying to, ah, cure you."

I: "Is that upsetting at all to you to think that your
health may not be now as good because of the treatment?

"It is in a way, but also I'm very lucky to still be alive, that they did what they thought they could do." (Robin)

Going through treatment is the start of a process of narrating a repair of self. The cancer is removed from the body and any stray cells are also destroyed. The metaphors used in the narratives are centred around the removal and destruction of the cancer. The narrative is of the successful treatment of the cancer, no matter how difficult and challenging going through treatment was. This narration of success is another aspect of the developing construction of a discourse of hope.

2. Evaluating Treatment

The second theme in this section is the evaluation of the treatment the participants received. Generally they described the treatment that they received as being "very good" or "the best". There were very few stories of health professional or institutional incompetence. I think this may in part be the result of the participants seeing me as representing the British Columbia Cancer Agency, the institution responsible for much of their care. The one story of professional or institutional incompetence that was told was Trisha's story of ongoing problems during treatment.

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93 This is especially the case when compared to the interviews that I did in 1987 (Mears 1988). In many of these interviews the women had horror stories about their treatment by doctors, nurses, or the hospital. This may in part be due to the shorter hospital stays required with the use of lumpectomies. Also, I hope that more general practitioners are aware of breast cancer and therefore the treatment of the women has improved.
Trisha waited until December for her first appointment at the Cancer Clinic. Her husband took a day off work and came to the first appointment with her.

"The radiation oncologist told us at that time that because my lump was small I would only need radiation therapy. Well, that’s what I wanted to hear, even though I had asked for copies of the pathology reports, two of them. I got copies from my family doctor.

And reading Dr. Susan Love’s Breast Book she had a section on how to read a pathology report. So in my mind the lump was not small. It was 2.4 centimeters, and they like to get them under one [centimeter]. . . . It wasn’t small it was stage II. That I, I had decided it was stage II.

And umm, so I was thinking it is going to be chemotherapy, because that is what she said in her book. But the radiation doctor said no, it’s small enough you don’t need chemotherapy and, so you can just have the radiation. Well, that was great news because I thought phew, you know."

Trisha started radiation therapy in the middle of January. She had read about radiation treatment, and found she did not have too many side effects. "It all went quite well."

"Then on the last day of radiation I also had a doctor’s appointment, to see the oncologist, the radiation oncologist. And there was something nagging at me. Because going in everyday for radiation I had been talking to different people in the waiting room, and I had talked to a lot of other women who I thought, 'Gee they’re just like me'. And, because they seemed about the same age, the same build, there were so many similarities. And we discussed our different treatments, and just about every one of them had had chemotherapy. And some of them had tumours smaller than mine, like two centimeters And it just nagged at me a little. . . . And so on the last day I thought well I’ll ask this doctor, the radiation oncologist, I’ll ask about that.

So on the last day I was in his office for the examination and I said, 'You know I’ve just been wondering, I’ve been talking to different women in the waiting room, and some of them have had chemotherapy,
and some of them didn't. And I was just wondering how the decision was made?'... Well he opens my file and within a second he said, 'Oh my God. I'm really sorry. I've made a mistake, you should have been offered chemotherapy.' What a shock. Well I knew that right from the beginning that I should have been offered it because I'd read the pathology report. He didn't. That's the first time he'd read my pathology report."

I asked Trisha how her chemotherapy treatments went. "Not very good. There were more mistakes made with that."

At the time she started her chemotherapy she also started going to a support group for women with breast cancer.

"It's been really nice to have each other to compare notes with... One of the people in this group had said something to me that really stuck with me. She's been really good to have because she's been through it before I was... I was a little nervous about it, and then she said to me, she said, 'Well I look at it as a gift because people before couldn't have had chemotherapy.'... And so I thought that was a good way of looking at it."

Trisha had a girlfriend who came with her for every chemotherapy treatment, and also stayed with her for the night.

"Then, ten days after I had my chemo, I ended up, I got a fever. And I phoned the Cancer Clinic, they said to do that if I got a fever, so I phoned them... They said, 'Well, how long will it take you to get in here?' and I said, 'About 45 minutes.'... They said, 'Oh, that's too long then you'd better go to your local hospital. Go to the emergency we'll phone and let them know that you are coming.' So I got down there, and they said, 'Oh, we've been expecting you.' Rolled me right, put me on a stretcher and put me on I.V. right away, like. It's dangerous, because ten days after your chemo your blood's down, white blood cell count is at about it's lowest. It's been knocked down really low. And so if you get a fever or something your body could be unable to cope with it, to fight it off... So people have died on chemo."

So Trisha was put in an isolation room for three days, but "It all turned out okay."
Trisha's second chemotherapy treatment had to be delayed a week because her white blood count was still low. She wondered why she would have problems building her white blood count up, because she "has always been a healthy person".

"They figure out your chemotherapy dosage by your body mass, by your height and your weight. So I said, 'You know, I lost 30 pounds over the last four months.' 'cause when I was originally diagnosed with breast cancer I started to get scared to eat anything. I got like anorexic. Everything I went to eat I thought this is going to be bad for me, this is bad for me. So I lost 30 pounds between diagnosis and the completion of my radiation. . . I said to this resident, 'You know, it bothers me why I would have trouble getting my blood count back up again'. I said, 'Could it that maybe because I lost this weight, maybe you got the body mass wrong, maybe they figured it on my previous weight. And so, maybe I go too much chemotherapy.' And he said, 'No I don't think so, but I'll certainly look into it.' So, nobody ever told me anything, nobody had ever said that they had made a mistake.

But when you go for your appointment with the doctor, and then you go for chemo they give you, they sometimes give you your file to take up to the chemo ward with you. And I read it and I found a letter on the file that he had written saying he had checked my, my weight, because I had asked it, the weight was fine but they had calculated the height wrong. . . So, that's why I ended up having an infection, and going in, because they had over-dosed me on the chemotherapy."

Angela and Susan told stories of physician delay, and Eileen a story of being released from hospital too soon after her mastectomy surgery. It is interesting that in these three stories it is the administration of the treatments that is the problem, not the treatments themselves.

In talking about their treatment the participants spoke about the doctors, especially the surgeons and oncologists, as experts in the field of cancer treatment. For example Karen stated a number of times during the interview said she "... had
faith in her doctors." The uncertainty of death can only be addressed by faith.

The discourse of hope centred on the trust and faith in the doctors' expertise was extended to the British Columbia Cancer Agency and the treatment they received there as well.

"Yeah, I've dealt with them [the British Columbia Cancer Agency] right from day one and, and I figure that, that at that hospital all they're doing is cancer. I mean there's all types of cancer but they're doing just cancer but in the other hospitals they're talking about T.B. or bone transplants or taking out a liver or taking out something, you know. And so, to me I think the Cancer Clinic is good because the doctors and nurses are all on one subject, cancer." (Virginia)

The trust in the experts and the treatment is a feature of many of the participant's stories of their breast cancer diagnosis and treatment.

Trisha's story of the problems with her treatment, resulting in her doubting its effectiveness, is a striking counterpoint. Despite the general feature of trust in the experts, a number of the participants felt lost in the medical encounter and compelled to do their own research on their illness.

The participants create in their stories the experts who are in charge of their treatment and care, and who they trust. There is no doubt the medical profession fosters this kind of trust to a degree (DelVecchio Good 1991, DelVecchio Good et al 1990). But it is also part of the construction of the discourse of hope. If the doctor really is an expert then there is a chance the cancer can be successfully treated. By constructing faith in the doctors who prescribe treatment, and therefore in the treatment, the women are constructing hope the doctors and their treatment
will get rid of their cancer and extend their lives.

A few participants evaluated their experience another way. They compared their experience to that of other people with cancer who did not seek out expert advice or did not follow the treatments suggested by the experts and have now died. Virginia, after talking about how secure she felt going to the Cancer Clinic, told this story,

"And they keep good tabs on you, they do check ups all the time, you know, they're right on top of it all the time so, so they don't lapse it, you know. 'Cause a friend of my mum's, her daughter had cancer the same time as I did and they live out in Pitt Meadows, but for some reason her doctor didn't follow up as much as my doctor did in the Cancer Clinic and about a year and a half after that she passed away."

Similarly, Jill mentioned a friend who had refused treatment.

"I did chemotherapy, I did radiation. But the Lord blessed those things. Umm, I know many take the natural route, go on grape juice or, that did not appeal to me. We just had a close friend who actually, August of '89 I started cancer treatment and at the end of August she, she died and she had gone that route. Don't ignore the help you can get from chemotherapy and radiation because we're finding that going the natural routine is by no means one hundred percent."

There is also another evaluation, which is an explicit comparison of the participants' experience with breast cancer to those of other women. Probably the most common comparison is that because they did not have to have some treatment their cancer was not as serious as those of women that had to have that treatment. For example, they did not have to have a mastectomy so their breast cancer was not as bad as someone else's. During

95 Pitt Meadows is a distant suburb of Vancouver.
diagnosis they learn from the treatment personnel which treatments are used for more advanced cancers (See Chapter IV). As well, from contact with other women who have had a diagnosis of breast cancer they learn that other women have had further treatments and more advanced disease.

This comparison also goes into the area of coping with the diagnosis. They say they are better off than other women with breast cancer, usually because their diagnosis "did not affect them that much", it did not change their life or have much emotional impact.

These comparisons are a way of demonstrating that the participant’s breast cancer is not as bad as the breast cancer of other women. Using this comparison is part of the process of minimizing their disease. It is also a way of creating hope for the future. For example, Leanne told the story of her mother-in-law who had been diagnosed with breast cancer shortly after she had lost her husband. So she was hesitant to tell daughter and son-in-law because,

"... it just didn’t seem the time to lay something else on them. Besides mine is kind of minor, you know, compared to her’s that is. And, umm, you know she has other medical problems besides, whereas I’m healthy to begin with ... I felt I kind of had something on my side, you know, whereas I felt some of the people I knew like her didn’t really have anything on her side, you know, and then when you lose your husband after 47 some odd years."

The comparisons go beyond breast cancer. The women compare their experience with breast cancer favourably to other people’s experiences with other conditions. For example Heather’s husband had just come out of hospital after having surgery for lung
cancer as she was going into hospital for her surgery for breast cancer. Heather was far more worried about her husband's lung cancer and said that his condition was "... much, much bigger" than her breast cancer. Constructing the story this way also gives the participants more hope of a cure or complete recovery, or at least a more promising life in the future.

The story of going through treatment has two striking, if almost contradictory, themes. The first is the description of the severity of the treatment and the suffering involved. The second is constructing hope about the future.

The adverse symptoms produced by the treatment are indications of the effectiveness of the treatment. The creation of hope makes the short-term suffering worthwhile and meaningful. The participants have faith in both the treatments and the professionals who administer them as being the best available to treat the cancer. And some of the participants compare their own case with others who are worse off to make the future seem bright.

This construction of hope for the future was discussed in DelVecchio Good et al (1990), which examines the way in which oncologists construct hope for the future in their own discourse about cancer. It appears from this research that a similar process is happening with women who have been diagnosed with breast cancer, although the elements of their discourse differ.

The women may incorporate the discourse of hope of the oncologists, which is shared discourse of the medical institution, into their narratives. Through narrating the story
of diagnosis and treatment the participants create and contribute to a developing discourse of hope. This may in part reflect the change in the conceptualization of the disease from cancer as a "death sentence" to cancer as survivable.

E. Stopping Treatment and Getting on with Life

The next section of the story of diagnosis and treatment is the description of the completion of active treatment and getting on with life. After completing treatment the participants continue with regular and fairly intensive checkups. Some of the participants also have to deal day to day with the physical consequences of their diagnosis and treatment of breast cancer. They also have concerns for the future and fear of the possibility of the cancer recurring. The fear of recurrence once treatment has been completed is the first of many challenges to the predominate discourse of hope as constructed through the story of diagnosis and treatment.

1. Completing Active Treatment

For some there was a sense of relief when the active treatment was finished, just not to have to go through any more treatment.

"As a matter of fact when, ah, Dr. Rose\textsuperscript{96} when they put me on the medication when I went in, umm, he said, 'Everything is fairly good,' and he said, 'I don't want to see you again.' So that was nice news to both my husband and I. It was very nice to hear." (Karen)

\textsuperscript{96} Dr. Rose is a pseudonym.
For others, including Anne, there was an uneasy feeling when active treatment ceased and they were no longer attending the Clinic every day or every few weeks. Anne said there was no bridge between the British Columbia Cancer Agency and treatment experience and the experience of being left on your own to get on with life.

It is as if, without the active treatments and the side effects of the treatments indicating their effectiveness, there is a chance the cancer will recur. Therefore, it is at the completion of treatment that some participants start to investigate alternative treatments, such as dietary and herbal treatments. Part of looking to alternative therapies is to continue some form an active treatment of the cancer and prevent a recurrence.

2. Attending Regular Checkups

Once treatment has been completed the participants attend their oncologist and surgeon for regular check ups. These are to determine if the cancer has recurred. The actual timing of the check ups changes, every three months for the first year and then every six months for the following years.

As these check ups are a medical procedure looking for a recurrence of the cancer, attending the first checkup can be frightening. Earlier in the chapter Leanne described how she felt going for her first check up.

Leanne felt better after her first check up, but other women are just as nervous. The reason is the possibility of detecting
a recurrence with each check up. Some of the participants tell
the story of a friend who has had a recurrence, like the story
Nancy told about Margaret.

As time passes the check ups become further apart. The
participants interpret this as an indication that the doctors are
not as concerned about the cancer recurring. The passage of time
since diagnosis is important in decreasing the likelihood of a
recurrence. The checkups and the way in which they are spaced
are used as markers of the passage of time. This is important.
Jill’s check ups had just been moved from every three months to
every six months and she was "feeling great". Another
participant said,

"And just going to my doctor every six months,
seeing him and that, you know, and then he sent
reports... I think now I only have to go, umm, I
think it’s once a year starting, it was every three
months and then it went to every six months and now I
think, now it’s going into the fourth year that I only
have to probably go in once a year and have him check
me over and he’ll send a report."

I: "Getting longer and longer time then?"

"Yeah, thank goodness (laughs). I get kind of
sick of going there (laughter). But otherwise it’s
just a closed chapter in my life." (Catherine)

"Now that’s over three years now and, umm, I feel
quite confident that if anything was going to show on
that side again as a result of not being completely
gone the first time it would have shown up by now." (Sarah)

"Yeah, that’s all I’ve been through is just the
regular check-ups and they [Cancer Clinic] discharged
me just recently."

I: "How does that feel?"

"Oh, it feels good (laughs) it’s quite a weight
off my shoulders. That’s for sure, yeah. Yeah now I
feel like I’m almost completely over it now, it seems
so, times gone by, and the five years\textsuperscript{97} has gone by
and, and I'm reconstructed and everything and so it
seems almost back to normal." (Angela)

The final mark in the time since diagnosis is what the
participants refer to as the "five year mark." About half the
participants talk about the importance of getting to the five
year mark. This point of time is said to be the point at which
the cancer they were diagnosed with will not return. When Amy
was asked if she remembers, or celebrates, the dates of her
diagnosis she replied,

"Yeah, well I'm waiting, you know, like they
always say five years clear even through that’s, the
people argue about that. But that has some emotional
comfort like I can hardly wait for August of '94
because that means my right breast theoretically is in
the clear (laughs). And it will be November '96 for
the other one. You know, yeah, so that is kind of like
a marker."

As in the process of diagnosis, time is an extremely
important element in the construction of this section of the
story of treatment. The more time that has passed since
diagnosis the less chance there is that the cancer will recur.

The participants use the institutional follow-up procedures
to mark the passage of time (Roth 1963) and to give validity to
their belief that the more time that has passed the less their
chance of recurrence. As more time passes between each check up,
from every three months to every six months, the participants
assume the physicians, the experts, are less and less concerned

\textsuperscript{97} There is a popular understanding that once a patient has
survived for five years they are cured. The five year mark is
arbitrary but commonly used by biostatisticians as a point of
comparison of survival rates over time or between tumour sites
(see for example National Cancer Institute of Canada 1995).
about the possibility of a recurrence. The passage of time, as marked by the institutional follow-up, becomes part of the construction of the discourse of hope.

On the other hand the participants have to deal with what they refer to as "scares". Scares are incidents that produce symptoms the participants fear may be an indication of a recurrence of their cancer. Some scares the participants take care of themselves and put down to being over-anxious and frightened of a recurrence.

"I think as time goes by you just kind of put it all in the back of your mind. But you still, every little ache and pain you get, like before I’d always ignore it, now I think, ‘Oh, I wonder if it’s, you know, coming back.’ You know it’s always in the back of your mind." (Lynne)

Other scares require medical investigation, which make the symptoms much more real.

"I try not to think, I still get butterflies and I get anxious the night before I go in to have [my check up]. Umm, ‘cause I had a scare. When my mum was sick, I had a scare, they tested, or were feeling around my other breast and they felt a lymph node and I could tell by the look on his face and he went, he said, ‘I think I better do a biopsy.’ And I mean that just, and so I had to wait a day to find out the results of that biopsy. And, ah, so everytime you go in it’s, you know." (Amanda)

These scares are challenges both to the repaired self that is cancer free and to the developing discourse of hope. They raise the possibility of cancer becoming a threat again despite all that has been done. This is the first hint in the narrative of living with cancer that there are multiple challenges to the repaired self and to the construction of breast cancer as a chronic illness that is survivable.
3. Living with the Physical Consequences of Having had a Diagnosis of Breast Cancer.

The other main theme in this section of the story is living with the physical consequences of having being treated with breast cancer. It is not only the breast cancer that produces many of these problems, but also the treatment of the breast cancer. These physical problems are constant reminders to the participants that they have had a diagnosis of breast cancer. Although they are hopeful that their treatments were successful, consequences of those treatments raise the possibility of a recurrence of the breast cancer.

The most serious and long lasting physical consequences are related to the surgical treatment for breast cancer. Most of the participants who have had a lumpectomy are happy with the aesthetic results of the surgery and had few side effects. Lisa commented that sometimes her breast gets painful. Amanda was not as happy with the results of her surgery, saying that the lumpectomy changed the shape of her breast significantly. Amy also had an unpleasant side effect of the lumpectomies in she lost the sexual response in both breasts. Some sensory loss in the breast is not unusual after a lumpectomy.

The number of side effects or problems related to having a mastectomy are not numerous. Jean's surgery did leave her with a numb chest wall.

However, many of the participants who had mastectomies were not happy with the aesthetic results. The distress of losing a breast as well as having had cancer is extremely difficult.
Christine said that she "felt mutilated" after having a mastectomy. However,

"But I found out, ah, with the relationships I had with these men [after her husband had died] that I wasn’t any less a woman because of having lost a breast."

One complaint of all the participants who used prostheses is that they were very expensive, and in some cases do not last very long. The main complaint about the expense concerns swim wear specially designed to be worn over prostheses. The participants believe someone is making money from their having to have a mastectomy.

Another complaint is that the prostheses are very heavy and hot. Sometimes they become very uncomfortable.

There are participants like Virginia who are very pleased with their prostheses.

Other participants, four of the 15 who had a mastectomy, chose to have reconstructive surgery.98

"Yeah, I bought the best prosthesis and I didn’t like them, I hated them. I was afraid that if we were in gym or something, they’d flop out on the floor... It was basically so, to get rid of the prosthesis and wear a top that you look half normal because you don’t look normal anyway ‘cause you’ve got these big ugly scars... I do have a boob. It looks like a boob, jiggles like a boob. That was it." (Denise)

"So it’s all sort of, umm, it’s fairly realistic looking and, and it’s, I found it’s very, it’s been very good for my self-esteem and it’s not such a hassle

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98 Reconstructive surgery is where a plastic surgeon will reconstruct the breast after a mastectomy. There are two main types of reconstruction. One type uses an implant, either saline or silicone, that is inserted under the skin. The second type uses tissue flaps from the abdomen or back to reconstruct the breast (Olivotto, Gelmon and Kuusk 1995). Most of the participants who had reconstructive surgery done had silicone implants.
to have a prosthesis. I was worried that the prosthesis was going to fall out. ... Yeah, much more convenient, yeah. Yes, it seemed more convenient to me. And relationships with men too. It's, it was like I, I wouldn't, I would never ever have tried to go out with a, somebody, with a guy at the time 'cause it was just too embarrassing to have to mention that I had one breast, so that's another reason." (Angela)

Reconstructive surgery is successful for most of the participants. However, Denise had to have her surgery redone. Stephanie had a number of problems with the implants shifting position and causing infections. To correct the problems she had additional surgeries, none of which was very successful. At the time of the interview she had resigned herself to the fact that her implants would stay very high on her chest. She had had enough surgery.

Some others mentioned being concerned about having silicone implants. Denise specifically chose to have saline implants. However, Angela, who had silicone implants, said,

"There's been a lot of press about the, umm, silicone implants too. And so that kind of worries me, I feel I should be doing something to find out more about that."

I: "Do you know what implants he put in?"

"Yeah, I've got silicone. ... They say they leak and they 'cause all kinds of things so, so I'll attribute my lack of energy to that, or my headaches to that, or something so it's been a real drag."

I: "It must be scary."

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99 There have been complaints from women with silicone implants that the implants leak and cause serious health problems. Many of these concerns and complaints were reported in the local news at the same time as the interviews. The issue of silicone became a part of the Subcommittee Report on Breast Cancer (Greene 1992). There have been a number of class action law suits started on behalf of women with breast implants against the manufacturers.
"Yeah really scary, yeah. I wonder, ah, I wonder like maybe in fifty years, if I live fifty more years, will it all of a sudden burst or something."

Those women who did not have reconstructive surgery commented that they did not want to have it done and that they were concerned about problems such as the risk of infection and problems with silicone. They would have considered reconstruction if they were younger, but not now. In their case they were satisfied with the prostheses, even if they were expensive.

Two participants who had had breast reconstruction surgery also had a second mastectomy to remove their remaining breast. In total there were five participants who had had bilateral mastectomies. Leslie had had two diagnoses of cancer, one in each breast, and had been treated with a mastectomy both times. She commented that having only one breast she felt awkward and lopsided and it was easier to have them both removed. She also said that "... it's better to have it off and you won't have that worry." Not only was she more comfortable but she did not have to worry about the cancer recurring in the other breast.

Catherine told a similar story.

"... 1991 I guess it was, kept going in for my mammograms and then, there was a lot of lumps in this breast [her remaining breast]. And they kept calling me back, you know. Well, I was really paranoid, you know, and I was really getting worried so I went in and seen the doctor and had this one removed and it wasn't, the lumps weren't cancerous. But I'm very glad to, I'd rather have none than one, you know. I really would. I really, I felt a 100 percent, I felt like a freak before. You know I was so happy to have them both removed."
Catherine is now considering having reconstructive surgery, but has not yet decided.

This process of making decisions about having a mastectomy and then whether or not to have reconstructive surgery is a process of reconstructing the body. The participants come to accept, most often, their new body. They redefine their concepts of femininity and wholeness. This is not an easy process and sometimes continues long after the treatment period is over\textsuperscript{100}. The redefinition of the body is part of the reconstruction of the self as a whole person.

The other physical problems related to the surgical treatment of breast cancer are the result of the axillary dissection. Immediately post-surgery the participants had to exercise their shoulder and arm in order to regain full range of movement. Some participants continued on with no further problems after the initial stiffness. For example, Jane a few months after her surgery went on to play competitive racquet ball.

A few participants had ongoing problems with the mobility of their shoulders and arms. This can become a very serious problem for someone like Rebecca who has another health problem, in her case Parkinson's, that also reduces mobility. Mary said:

"I went to a trainer, umm, who knew nothing about this field but she knew enough to start low on the scale. I was lifting two and a half pound weights. That was for a long time and just so I could get a wide range of movement. So I have complete, whole range of movement, and a lot of them [women with breast cancer] can't, they don't have that back. They can live a long

\textsuperscript{100} A fascinating account of the reconstruction of self is Audre Lorde's \textit{The Cancer Journals} (1980).
time without full range of movement. But if you're
trying to heal your head as well as your body it's very
important, I feel, to get as much of yourself back as
possible."

Another problem is probably the most commonly mentioned and
for a few women was very serious. After the lymph nodes have
been removed from under the arm there is a chance the arm will
start to swell as a result of the accumulation of fluid. This is
called edema, and can occur at any time after the surgery.

"I have edema in my arm. It started about a year,
I think, after my surgery and I had it just in my upper
arm and to my elbow and. Ah, when I mentioned it to a
doctor at the Cancer Clinic then said, 'Well we have
therapy at the Cancer Clinic.' So then I started
taking therapy and I was going quite often... And
then, ah, one summer we went on a vacation back to
Manitoba. And it was hot, and I don't know whether it
was because of that, or what it was, but when I came
back I noticed that the swelling had gone down into my
lower arm and my hand. But then I took more therapy
and, ah, I have my own machine at home now that I use
all the time, but I still go into the Cancer Clinic
every month or two." (Christine)

A little later Christine commented further on the impact of
the edema. "My arm is fatter than the other, this is quite a
nice looking arm, this one is fat."

The other physical consequences related to treatment were
loss of energy, continual tiredness and frequent colds and flu.
Jill commented, "if I get around anybody that had the slightest
cold I would come down with a terrible cold."

These physical consequences of the treatment of breast
cancer are part of day to day reality for women who have had a
diagnosis of breast cancer. In telling the story of diagnosis
and treatment the participants end the story with an account of
these ongoing problems. On the one hand they are involved in
marking the passage of time since their diagnosis, and on the other hand they are dealing day to day with the physical consequences of their treatment.

No matter how successful their treatment may have been these physical problems are constant reminders of the cancer and the possibility of recurrence. In this way many of these problems are challenges to their reconstructed selves as well as to development of discourse of hope for the future.

F. Conclusion

The stories of diagnosis and treatment told by the participants are remarkably similar. In this story they are narrating an event that disrupted their lives and lead them to make decisions about modes of treatment and styles of coping. At this point in the illness narrative it is important to describe how one has made the correct decisions about treatment (Price 1987, Early 1982). If the correct decisions have been made then there is less chance of the possibility of a recurrence.

Through the telling of the story of the treatment process the participants start the biographical work (Williams 1984, Bury 1982) of reconstruction. The work involves both the reconstruction of identity, coming to terms with being a person who has had a diagnosis of breast cancer, and of the body, separating the cancer from the body and redefining the body after the trauma of treatment (Mathieson and Stam 1995).

An element of similarity in the structure of the narratives is related to the interaction between the participants and the
health care system. With a provincially funded health care system and centralized cancer treatment facility most of the participants go through a very similar experience. Treatment protocols, such as the standardized follow up policy, not only result in a similar experience, but also provide the participants with similar markers by which to gauge their progress.

The treatment policies of the institutions may also result in similar information being passed on to the participants by the physicians and other treatment personnel. For example, if all the doctors discuss the size of the tumour as being a critical marker in making decisions about the severity of the cancer then the participants will include this as part of their narrative.

The most important point in the story of diagnosis and treatment is the participants' constructions of a shared discourse of hope. It is through the process of being diagnosed and treated that the participants learn the structure of this particular discourse. They learn the discourse from the cultural understanding of cancer, as well as through participation in the treatment process. The participants are sharing in the oncologists' discourse on hope (DelVecchio Good 1991, DelVecchio Good et al 1991) as well as creating a new discourse of their own.

The process of minimalizing the cancer, making it small and not having spread, and of constructing successful treatment all contribute to this shared discourse. The discourse on hope transforms cancer from a death sentence (Patterson 1987) to a disease that can be survived (Gordon 1990). This discourse of
hope provides a framework, making the biographical work much easier. However, even while the discourse of hope is being learned there are challenges, reminders of the cancer and the possibility it may recur.

As the analysis continues I explore how the participants elaborate on and use this discourse on hope they have learned during the process of diagnosis and treatment. As well I describe some of the challenges they face while trying to maintain hope for the future and their own survival.
Chapter VII - Schemata for Constructing Narratives of Living with Having Had a Diagnosis of Breast Cancer

This chapter explores how the participants constructed their accounts of their breast cancer experience within the context of their personal life stories. In constructing these accounts to include the diagnosis of cancer they rework their personal biography. They repair their life biography to account for their experience with breast cancer. To do this almost all the narratives cover topics such as why the participant got breast cancer, risk and cause of the disease, the effect of the diagnosis on day to day life, and what the future holds.

In the interviews the stories of the effect of the diagnosis on the participants' lives came after the story of diagnosis and treatment, and were built on many of the same themes. The predominant theme is the discourse on hope. As the story continues the discourse of hope is altered to accommodate the individual's life course and life experiences. It is as if hope for the future takes on a slightly different meaning for different participants as they move further from the period of treatment.

The accounts of life after the completion of treatment do not have the strong similarity of structure of the stories of diagnosis and treatment, and are spread throughout the interviews. These accounts are constantly reformulated as new information comes to light and new events occur in each participant's life. There are however some remarkable
similarities between the stories.

An analysis of the similarities and differences revealed four cultural schemata, each used by at least three participants. The four schemata are:

- Breast Cancer as a Point of Change;
- Breast Cancer as an Acute Illness;
- Breast Cancer as a Terminal Illness; and
- Breast Cancer as a Part of Life.

These schemata are not mutually exclusive. A few participant's stories incorporate more than one schema. This indicates the flexibility and changeability of cultural schemata.

There were also three accounts which did not use any of these schema. I discuss them separately. This seems to indicate that there may be more than the four schemata identified in this research and the use of particular schema may change with a changes in the historical or social context.

A. Construction of a Discourse on Cause

Before describing these four schemata I review the construction of a discourse on the cause of breast cancer. This discourse was present in all the schemata. Most of the participants made some attempt to account for their personal experience with breast cancer. As is also found in other research, the ideas of risk and cause presented by the participants are based in personal experience (Gifford 1986;

\[101\] Rebecca's narrative is interesting in that she was not interested in trying to determine what may have caused her breast cancer.
Balshem 1991, 1993) and provide insight into the cultural construction of breast cancer.

The specific factors participants identified as being linked to breast cancer are either present in their lives, and therefore increased their personal risk of getting breast cancer, or are absent, and should have decreased their risk. In this way the participants construct a personal risk profile, taking into consideration many different risk factors.

For example, some participants stated they have a family history of cancer or breast cancer\textsuperscript{102} and that this increased their personal risk of getting breast cancer. They may state this either specifically simply say that "someone in the family" has had cancer. Others stated that they were the first person in their family to have had a diagnosis of cancer and that their personal risk should have been lower than that of a woman who had a family history of cancer or breast cancer.

Some participants interchanged the words "family history" and "genetic"\textsuperscript{103}. There is no doubt that the discussion of family history is one way of talking about the passage of cancer through genes.

Participants also considered age. Those who were young when they were diagnosed, in their thirties or forties, felt that it

\textsuperscript{102} For most participants having a family history of cancer, not specifically breast cancer, was important. Also, a family history usually referred to one of more relatives having had cancer.

\textsuperscript{103} During this study the discovery of the breast cancer gene BCRA 1, which was highly publicized in the local media. (Canadian Breast Cancer Research Initiative 1994).
was unusual for them to be diagnosed with breast cancer because it usually affects older women. This lead some to consider other possible risk factors to account for their cancer.

Those who were older knew the risk of getting breast cancer increased with age and that they were at greater risk, but still went on to explore other possible risk factors.

Participants weighed various factors in their reproductive health histories, for example whether or not they had had children. Those who had had children, or had their children at a young age, said this should not have increased their personal risk. One participant said she had breast fed all her children and did not have any problems, and this should have decreased her risk of breast cancer. Another said she had had serious medical complications after the birth of one of her children which might be related to her breast cancer. A number of participants said that they had used oral contraceptives and were concerned this may have increased their personal risk.

Talking about reproductive history is one way of linking the breast back to the feeding of children and its role in reproduction. The suggestion is if the breast fulfils its role in reproduction then there is less chance of breast cancer developing.

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104 Saillant (1990) also found breast feeding mentioned as a possible protective factor.

105 This fits with the cultural construction of the female body as a receptacle for reproduction (Martin 1987).
Most of the participants made some comment about their diet in relationship to being diagnosed with breast cancer\textsuperscript{106}. Some commented that the fat content in the diet in North America is too high, and this contributes to the higher rates of breast cancer on this continent. Others talked about whether or not they had a high fat content in their own diet. Participants also identified additives in food, such as artificial sweeteners and antibiotics in meat, being related to increased incidence of cancer in society and possibly related to their own diagnosis.

There are two variations on this theme of diet. First, diet is related to whether one is living a healthy lifestyle. Being fit and eating well should lower the personal risk of cancer. Second, elements in the diet, such as fat or additives, may be themselves carcinogenic.

Many of the participants mentioned environmental pollution in their communities, which may have increased their personal risk of getting breast cancer\textsuperscript{107}. Factors they mentioned were environmental pollution, radiation exposure, electromagnetic fields, and chemical contamination of the water and food supply from use of pesticides on fruit and vegetables.

As with diet, with environmental pollution there are two variations on the theme. First, an environment loaded with

\textsuperscript{106} Research on the link between diet and breast cancer has been increasing, and has been well reported in the media.

\textsuperscript{107} This is an area of increasing interest (Patterson 1984), and is definitely a concept present in the lay discourse of cancer (Salzberger 1976, Dornheim 1991). Recently, Greenpeace published a report arguing about a link between Chlorine in the environment and breast cancer (Thornton 1993).
pollution is generally unhealthy. Second, some of the pollutants may be carcinogenic.

A final predisposing factor for the participants is the sense that there is a precursor of cancer, that there is a cancer "seed" present in everybody. If one is healthy and strong the body, usually specifically talked about as the immune system, will prevent the seed from developing into a full cancer. Countering the predisposing factors referred to above, for example a healthy diet can maintain good health and prevent the seed from growing.

In the stories these predisposing factors alone do not cause cancer but rather create a susceptibility to the disease. Even those factors that are described as being carcinogenic need something more to actually produce the cancer. What is needed is something to trigger the cancer to start growing. This is similar to concepts described in other research on lay beliefs about cancer (Balshem 1991, 1993; Cornwall 1984). In some cases the trigger is specifically identified.

"Then as I neared the end of my treatment I was thinking, I'm not satisfied with just finishing the treatment, and saying, 'I hope I don't get it back.' Particularly because I'd met quite a few people with recurrences at the Cancer Clinic.

So, I thought, I'm going to do something about it not getting it back, and changing my lifestyle. Even though we don't know what causes breast cancer umm, in the reading I've done there's a lot of, argument that it is, it could be caused partially by high fat diet. . . When I reflected on what I'd been like before, how I'd treated my body I thought first of all a lot of

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108 The immune system is becoming more predominant in the discourse of cancer, which may reflect the general increase of use of the immune system as a metaphor for maintaining health and well-being (Martin 1994).
times I'd been eating on the run, and eating high fat foods, and umm, living a very stressful life, long periods of time, and not getting enough rest. And so I thought that's why my immune system, this is my theory, that I just stressed my body out, and didn't fuel it properly, and so my immune system got weakened, and couldn't deal with the number of carcinogens that are going through us all.

And so I decided that I'm going to try to listen to my body and take care of myself basically. I've done a lot of reading on it, and I've gone back and forth not really sure yet exactly where I'm going. But I've certainly been focusing on getting proper rest and trying not to be stressed out, which is easy when I'm not working, been doing a little meditation, and a real focus on nutrition." (Trisha)

Stress is probably the most commonly mentioned trigger. Another commonly mentioned trigger is an injury to the breast.

In the stories these factors are employed to construct an personal susceptibility, or risk, of getting breast cancer. The schema integrating breast cancer into a personal biography include an account of the cause of breast cancer using many of the factors described above. However, it is not just the risk of getting breast cancer, but also how the construction of risk effects the construction of possibilities for the future, which is interesting.

B. Breast Cancer as a Point of Change

The stories using this schema construct the diagnosis of

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109 This was the most commonly listed cause in the Pre-Forum survey done by Support and Networking subcommittee of the National Forum on Breast Cancer and presented at the National Forum on Breast Cancer in Montreal on November 14 to 16 1993.

110 Chavez et al (1995) found an injury to the breast as one of the factors list by immigrant women. However, an injury to the breast as a cause for breast cancer is not part of the medical discourse.
breast cancer as a point at which the participants re-evaluated their lives and made changes.

Anne and Trisha, and ten of the participants in the short interviews use this schema. In their stories they describe how being diagnosed with breast cancer has made them look differently at life and change some of the things they did. Diagnosis is a point at which the participants are brought face to face with their own mortality. They re-evaluate their lives as a result of thinking about the possibility of their deaths, possibly in the very near future. Being diagnosed with breast cancer is a point of disruption in the women’s life stories. This is much as in the narratives of people who have been diagnosed with other chronic illnesses (Williams 1984).

Amy, who had been diagnosed with breast cancer on two different occasions, talked about how she felt after her first diagnosis.

"Oh it changes your life. I mean, you know, you’re in a different universe after that because you’re sort of brought face to face with your own mortality. I was only 38 at the time and I thought I was indestructible and I (laughs), but I thought, you know, I don’t have to think about the possibility yet, except I did. So, I mean it just changes the way that you look at everything, umm, that’s what I found.

Well it, for me I found it, umm, it sort of, began, not an intense process, but a process of questioning about the way I lived, my values, you know. And I found it ultimately to be a fairly liberating experience because you start to, you know, see your life in terms of well, gee, I could be dead in ten years so I might as well try to live the way it feels good to me rather than be governed by other people’s values and expectations from the past, and parents, and stuff. . ."
Amanda described how she and her husband had separated six months before her diagnosis, and then went on.

"I think with me getting sick it made him re-evaluate, umm, how he felt and it certainly made me. It’s getting to the point that, and wondering, you don’t know at one point if you’re going to be terminal. When they do the tests, when they operate then they had to test the lymph nodes, well they took a week to do. They’d done the lumpectomy and so on, and they figured they got everything out, but they had to wait then for the lymph nodes. And if they’re in the lymph nodes they it’s, that’s another story, you know, during, even during all that time you just don’t know, if you could be terminal or whatever, so you really do re-evaluate your life and what it’s all about, and what’s important."

With a diagnosis of breast cancer these women’s lives become uncertain and death a real possibility. They are afraid that even if the cancer is successfully treated it may recur. Therefore they go through a process of reevaluating their lives, both to try to prevent a recurrence and to live a life that is fulfilling, a life that they want.

These women’s descriptions of this process of reevaluation include discussion of what may have caused the cancer. This discussion is a reflection on their lives and health, in an attempt to identify those factors which may have contributed to the development of the tumour in their breast. Most participants identify specific factors in their lives and health histories that are related to their cancer. They link these factors together to form narratives of personal risk and adversity resulting in the development of a cancer.

A sample account exemplifies how this group of participants construct their personal predispositions and triggers. Jill described how she had had many health problems during her child-
bearing years, and as she spent much of that time as a missionary in third world countries she had not received adequate health care. She described her current diet as being very good because her family, as a result of their religion, were vegetarians. She used very little fat in cooking and did not eat milk or oil. She said, "I don't know how much diet has anything to do with it, and I'm not saying that diet does have anything to do with it, but we have been very careful."

Jill listed a number of her family who had been diagnosed with cancer. Of her mother, who died at 49, she said:

"... she didn't live long enough to find out if she was carrying the cancer germ or virus but, I understand it, it's a virus we all have and it's when our immune systems are low that the cancer starts growing... I don't know what made mine grow."

Later in the interview she described a disagreement between family members she found to be very stressful.

"I think of that as being a very traumatic time in our lives, and... they [doctors] did say, the cancer usually has begun years before you notice it, it's a very slow growing thing and that would put it back to about that time."

She was diagnosed with cancer after going to the doctor about an injury to her breast that did not heal.

"Yes, it was in March or April. I was running after all the lights were out from the bathroom to the bedroom... I knew where the door was, I thought, and I hit myself very hard on the side. It swelled, but I thought that anybody that does that can expect that. By the end of July it was aching and it didn't, I could tell no difference looking at it or anything, so I went to a doctor."

Some of the participants talk about making changes in their lives to deal with some of the factors they have identified as predisposing them to, or triggering, their cancer. They
recognize that some factors, such as family history, are not amenable to change and have to be lived with, while others, such as diet and lifestyle, are. The point of making changes is to improve their health, including their mental health, and/or to strengthen their immune system to give them a chance of preventing a recurrence or to assist their recovery if they have a recurrence.

Some participants change their diets and start to take vitamins or other dietary supplements to prevent cancer, as Anne did. Leslie had been to Mexico for a cleansing and diet program after being diagnosed with breast cancer.

"...I'm just on a good diet now. I changed my diet and take my vitamins. And keep it up that way, and I feel just great. I've got more energy than I ever had before. ... I stay away from all the fatty things, you know. And fried foods and like, umm sausage and that, you know, I don't eat any pork and no more coffee. I cut that all out, so coffee always made me feel kind of funny anyways, so I cut that out completely and, umm, what else have I been doing? Lots of fruit and vegetables, you know. I eat a lot of that, and sort of staying more to the lighter side of things, you know, I feel good."

The participants also discuss factors which are not related to the construction of a personal risk, but rather to changes in personal values and lifestyle. Reflecting on their experience of having had a diagnosis of cancer some of the participants talk about developing an increased awareness of their own health and bodies. After being asked in the interview if having had a

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111 In the interviews there were a number of participants who said they removed pork from their diet. In some cases it was due to the perception of pork having a high fat content, but in others it was an aversion to the taste. No other meat, except possibly "greasy hamburgers" was mentioned as often.
diagnosis of cancer had changed anything in her life Jill responded,

"I don't know, I hope it has helped me keep my priorities straight. . . I have always, it's very easy, I am (laughs) a project person. I get a project going and that I'd like to finish before I go to bed. And I have, I have learned to listen to my body signals, get more rest."

Other changes are made in attitude, lifestyle and values. Life is described as becoming "more precious" and the participants talk about making choices to do more of the things that they enjoy doing. Some of these changes were dramatic, for example, changing from being a well-paid secretary at a downtown company to being self-employed and living on a farm in the county. Others were much more subtle.

"Yeah, you do, you appreciate your friends so much more and, you know, your spouse and everything (laughter) you just appreciate waking up everyday. You know, you think, 'Oh, another day.'" (Lynne)

"That is one of the most important things, that you do have to love yourself, caring for yourself, and now, before I, before I thought of everybody else, and then after me. But now I don't." (Allison)

"I used to take piles [of work] home. On weekends I always worked. . . You know, and now I don't take any baggage like I don't worry, before I used to worry. 'Oh, did I, did I do this right? Did I do that?' I don't worry about [it] anymore. That isn't important. It isn't important to me, yeah, it's a real turn around." (Jennifer)

The following are some examples of stories showing how the participants integrate their construction of cancer, their reflections on their lives and the changes they have made.

Amanda described herself before her cancer as being insecure, having low self-esteem and being a dependent person who was always trying to be all things for everyone. As a result she
was bulimic and "abused" her body. After her diagnosis of breast cancer and a year’s separation from her husband at the same time, "I feel a lot stronger as a person going through all this. I feel that there’s nothing I can’t do."

When talking about what caused her breast cancer she was puzzled because she was the first person in her family to have a diagnosis of cancer, and she was relatively young.

"Oh yeah, and I mean it was such, I mean not that forty is that young, I guess, but you don’t expect, you don’t expect it to happen. . ."

Well I, I definitely believe stress has an awful lot to do with it, you know, there’s no question. The size of my lump the doctors figured it would take eight years at a normal growth rate to get to that size which was like the size of a pea. Well, if I look back from the day I was diagnosed, eight years previous, that’s when we, the market fell and we lost our house and my husband’s in real estate which was terrible, so there was a ton of stress then and it’s, I think, I think it’s in there I think it’s in your body but depending on your environment, your genetics. . ."

Now she is trying to deal with the stress in her life.

"Umm, I try and really watch it. And I tend to internalize things, I kept things inside, I didn’t say anything. . . I, you know, I was trying to be most accommodating with everybody and now I look at it and if it’s not going to work for me then I’m not going to do it, and, 'I’m sorry, I can’t do it,' or, you know, it doesn’t work, instead of me changing everything around in my life to make it work for them, I won’t do it anymore. . .".

Robin talked about possible causes of breast cancer and cancer in general at different points in the interview. She expressed a concern about the high incidence of cancer in Canadian society.

"And I think probably the vegetables that we eat and they’re spraying all the chemicals on I think that’s why so many people are coming down with cancer. I think it’s in the air from all the, ah, pollution. And all the sprays they put on all the vegetables, umm,
everything. You know, so many things out there that are probably giving us cancer, or going to kill us eventually. 'cause there’s too many people, there’s too, there’s far too many people with cancer, you know, it’s scary. You don’t even like to ask 'cause, so many of my friends have had cancer.

Yeah, it makes me think maybe it’s inherited through different families, like breast cancer is inherited through families like my boss’s wife, umm, all the women in her family have breast cancer, a lot of them, all the sisters, umm, the aunts, and she said when she found her lump, which was sort [of] in the middle of the breast she was not surprised one bit. And, ah, I think a lot of it is inherited... 'cause I think somewhere, somewhere’s way back I think someone has probably had breast cancer in my family."

She also talked about her diet before her diagnosis and how she has changed it.

"'Cause before I was, umm, when I was like 38 when I found out I ate a lot of diet stuff, a lot of nutra sweet, a lot of diet coke, a lot of diet pop, diet ketchup, you know, 'cause you want to be thin. A lot of junk food, a lot of fried food, a lot of hamburgers and chips and, umm. I figured [after the diagnosis] if I was going to have sugar, I’d have the real thing, if you’re having to have pop have the real thing, umm, eat a lot of vegetables, a lot of fruit, umm, stay away from pork, beef, eat a lot of fish, eat a lot of chicken, yogurt is supposed to be good for you, umm, stay away from all that diet stuff. You that how I think I got, got cancer in the first place. Nutra sweet, I lived on that stuff 'cause I didn’t want to put weight on. Any, any kind of artificial sweeteners stay away from. It’s dynamite."

However, more than her diet has changed since her diagnosis of breast cancer.

"No, you learn to, you learn to worry more about yourself, yeah, than before, I was always worried about other people before. Well I was always worried about what other people thought, umm, if I did something I was always worried, umm, that they might not like it or, like just take for instance if I want to go out now at dinner time and I phone my husband at work and say, 'I’m going out grab a sandwich.' I do it. Whereas before, well I can’t do that because, you know, he’s coming home for dinner type of thing..."

And then when you get so sick and then you realize
well, gee, I could actually buy the farm, you know, and I could get a reoccurrence next, next week, I don’t know, who knows. You know, so why not enjoy yourself now."

Fear of a reoccurrence makes the participants nervous and anxious before they return to their physicians for their regular checkups. They mark the passage of the years since their diagnosis, much the way Anne marked that one year had passed since she had been diagnosed.

One way of marking time is the lengthening of time between checkups. This is seen as the physicians, the experts, being less concerned about a recurrence. Many are looking toward passing, or have already passed, the "five year mark." They feel that once through this point, their chances of having a recurrence have decreased and the chances of living longer have increased.

Some participants, while acknowledging that a recurrence may happen, are concerned there is too much attention paid to death as the only outcome of a diagnosis of cancer. They have found that the word "cancer" has been equated with death, and yet they are very much alive.

The use of the label "cancer survivor" is also problematic, in that surviving seems to imply one is just hanging on, whereas they feel they are managing very well. Their personal construction of breast cancer is as a disease that they are living with or have beaten, not a disease they are dying from.

The final account in this group demonstrates one participant’s construction of her cancer and the integration of her diagnosis into her life. Amy has had two diagnoses of breast
cancer. When asked what she thought might cause cancer she replied,

"Oh, gee, I don’t even, I don’t know, there’s just so many different things, some think too much fat in your diet, too much stress, you know. Starts out a very, very cellular level, you know, one cell makes a copy of itself and that triggers, I mean there’s so many different ways of approaching it. You know, I was interested in a Newsweek article, when did it come out? It was about a year ago or so, that in Japan there’s not that much breast cancer because women eat a lot more fish, and they get more fish oil. And apparently vitamin A can help quite a bit so I started taking like a vitamin A supplement, cod liver oil. Umm, I don’t know, like what seems for me to be a real culprit is a lot of fat. An excessive intake of fat, you know, that’s why I’m trying to keep it down.

What some people would say is you bring it on yourself sort of thing ‘cause you’re all stressed out. And I thought, ‘Oh, it’s not true.’ But that made me very sad to think that I would, somehow, I contributed to my own [cancer] . . .

But on the other hand I do like the idea that if you have a positive attitude that, that somehow, you know, gives you an edge on fighting your illness. . . . Like about a year before my cancer was diagnosed the first time, like I was going through an incredibility painful divorce. I was so depressed and so miserable. . . . And then I get this vague idea, ah, maybe you know that sort of non-stop year of bad feelings kind of maybe lowered my resistance or something. That one little cell that normally would have been picked up [by] the immune system and destroyed got through the barriers somehow, you know.

So, ‘cause, you know, I was reading somewhere that the body constantly makes cancer cells, but the immune system destroys them. It recognizes them as a foreign object and I think well, who knows? Maybe that was, because I was so upset for a whole year that it’s, you know, maybe it was a contribution. . . . And you kind of wonder, you know, all the chemicals in the environment, you know, like if I eat chicken, all the chickens are treated with antibiotics.

On the whole, you know, it’s been, like it’s been a heck of a . . . to clean up my life, to try and lower the stress, be selfish, like do things that make me happy. You know you get a little more fatalistic, well hell if I’m going to be dead in ten years I might as well enjoy myself (laughter) you know, but on the other
hand like I did have an urge to get my financial stability very strong. 'cause as I say the fear of being poor and dying is not a nice prospect, you know."

Shortly after her first diagnosis with breast cancer she modified her diet.

"... Like you stop smoking, stop with the heavy fats and all that. It's not that easy to do but, you know, you take vitamin pills, not overdoses, but, umm, you just pay more attention to your body... Umm, I don't eat pork anymore, I very rarely eat beef and I, umm, I really would like to become a vegetarian, like a real vegetarian."

She also talked about changes she had made in her values since being diagnosed with breast cancer.

"Yeah, I guess it's the important things like it became very important to me to sort of, umm, be nice to other people around me. You know, to try and develop, it was like a really warm thing, strength, and I guess, whatever. Like people became much more important, my relationships with people, sort of, to feel good along that level.

And I, I didn't become totally anti-materialistic but I, my way of thinking because like, why do I need three winter coats when one will do, you know? A more simple lifestyle became more attractive to me, like I didn't want to be encumbered with Visa bills and striving after an opulent lifestyle. Like that really surprised me, I guess it's sort of a shift in material values.

But on the other hand it was almost funny like, in sense I became very careful with my money after that because I had the suspicion, well, I could be really sick and poor. So I started to really put money in my RRSP, and pay down my mortgage, you know, and get really smart with my money... .

So I wanted to build a little security thing around me, you know. But, umm, mostly it's just been, just the reaching out to people. The wanting to reach out and to get along, and you know, toward people, 'cause, ah, I don't know it was, it was really pleasant. Like I used to be, you know, before the surgery... I would have periods where I could be real sort of an abrasive person, like ignoring people and stuff like that, and I didn't want to be like that anymore... I don't know it's just not, it's kind of subconscious thing like if you're not sure how many
years you’ve got left, you might as well try and enjoy them."

The experience with cancer has brought Amy face to face with her own mortality. She realizes the cancer may recur. She is concerned that, "... if my body is capable of producing the cancer cells in my breast it can do that in my lung or somewhere else."

"Like I have to go for a mammogram every six months. And a couple of days before I go, I always go into the fear mode, you know, ‘What if they find something?’ ’cause my surgeon said, umm, ‘Because it has achieved separate tumours in your breast, so if you get another one’ I mean, he said, very chilling words, he said, ‘Our course is clear.’ But which he meant mastectomy, so I thought about that, and that’s been source of fear too. Umm, so yeah, every time I go for a mammogram or something there’s always that. And one thing too, like I guess, like I’ve got this real fear of death.

Like that’s a source of real anxiety to the point where I was almost thing I should, umm, oh, I don’t know, get a little counselling on how to deal with the fear of death. Cause the whole cancer thing has kind of brought it right in from of my face and I have to confront those fears, those awful fears they really are."

Getting to the "five year mark" is very important to her. The dates of her diagnosis pass much like birthdays. She sees getting to the five year mark as a "solid accomplishment" that will mean that she can expect to live quite a bit longer.

Despite being very aware of the threat to her life, she wants other people to understand that cancer is not an instant death sentence "... a lot of people get cured... it’s not instant death." She does not want to be labelled a "cancer survivor", she does not want other people’s pity.
For the participants who use this schema the construction of cancer in their story is that of cancer being a disruption in their lives and a point at which they reevaluate their lives and make changes. Having a diagnosis of breast cancer brings the participants face to face with the possibility of their own death. Coming to terms with the disruption and the possibility of death is described in terms of overcoming an adversity, and dealing with adversity changes them as people.

These stories include a discussion of the future. A future after a diagnosis of breast cancer is uncertain. The women may have a recurrence. They may die. The participants talk about women they know who have had a recurrence and have died, and about others who have survived. Talking about making changes in their lives, either to prevent a recurrence or to make better lives, is one way of trying to make the future certain.

Creating some certainty is a way to create hope for the future. These stories are optimistic, to a point, and are a very good example of how the participants modify the discourse on hope learned earlier. The earlier formulation dealt specifically with the cancer itself and its treatment. The participants add to the discourse elements from their personal lives and changes they have made to their lives. It is interesting that in these narratives, while the concern about recurrence is present, it is the fact that cancer can be survived that is dominant.
C. Breast Cancer as an Acute Illness

The accounts using this schema construct the diagnosis and treatment like an acute episode of ill health rather than a chronic or life-threatening illness. Four of the 32 participants used this schema.

The main characteristic of these stories is that the cancer is described as being "over and done with", there is no concern about it recurring. The cancer, the tumour, is constructed as a discrete entity that either had a specific cause which will not happen again or which has been successfully treated and therefore will not return.

Two participants attributed their cancer to a specific cause which is unlikely to happen again, so the cancer will not recur. In the first case Susan explained that she found the breast lump one year after she had been hit on the breast.

"You see, at work I ran into a metal pipe and it hit me right there [indicating her breast]. And I was sore, oh, for a couple of weeks, it was bruised and sore. And then it was oh, maybe, almost a year later when I discovered the lump. And I just thought oh, oh yeah, my dog, well we had two dogs that were hit by cars that died of cancer. Yeah, and a month later the one [dog], this lump started forming right where the car hit him. And we took him to the vet and it was cancer. And my mum always attributed a lot of cancer to injuries, the tissue gets damaged and doesn’t heal properly."

The cancerous lump was at exactly the same spot as the injury. She had a lumpectomy, radiation and chemotherapy. When asked if returning to see the doctor for her regular checkups made her anxious she said,

"No, not really. Umm, I guess because I keep checking myself too. And, ah, I haven’t really worried about it. I guess because the surgeon was confident that he got in all and, and with only one lymph node
affected, he felt pretty sure. Umm, he wasn’t a gloomy person, you know (laughs), he, umm, but I guess that’s why, you know, I don’t really worry too much.

Yeah, I think if, if you were to sit at home, be thinking about it all the time, you’d dwell on it. Then it would be more upsetting but if you’re kept busy you don’t have time to do that. And then, you know, I’ve heard of some of the people that, you know, have had breast cancer and then they only did a lumpectomy and they, they’ve been fine for years. So, ah, the surgeon, he said that there is the odd case where another lump develops and stuff. But umm, I guess because I, I really believe mine was due to an injury that, ah, it probably won’t develop another one."

Susan has continued on with her life. She is very busy and active. Susan and her husband run their own small business and usually work six days a week. She considers the breast cancer like any other surgery or illness that has interrupted her normal life.

"I don’t know whether it would be very important. I don’t know, maybe it’s because I’ve been through a broken leg and all these kind of things, and to me it was just another necessary surgery, you know."

In the other case Jane explained why she got cancer.

"But I think the reason, well I pretty well know the reason I got mine is because I, umm, took the estrogen replacement therapy. Umm, I had started it ten months before the lump was found and, oh, I was quite, you know, enthusiastic about taking this therapy because I didn’t want osteoporosis. And this was the newest thing at the time and I was quite happy to take it. But I think at that time they didn’t know that, umm, people with, I had had these little, umm non-malignant cysts taken out . . . I think one of the criteria now is that you, if you do have, had those then you don’t take the estrogen replacement therapy. So, I think that was a mistake on my part, I shouldn’t have taken it."

As soon as she was diagnosed with breast cancer she stopped

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112 Estrogen replacement therapy is sometimes prescribed for post-menopausal women to prevent osteoporosis and heart disease (Love 1990).
estrogen replacement therapy. Jane had a mastectomy, but no other treatment. After her mastectomy she started on a graduated exercise program using weights. Her physical fitness before the surgery and her use of this exercise program after surgery are the reasons she felt she recovered as quickly as she did. Her life has now returned to normal and she is as physically fit and active as she was before she had her diagnosis.

About six years had passed between her diagnosis and the interview. During the interview Jane was asked to talk about this passage of time since her diagnosis. She replied that,

"I've heard people say that after five years you're okay and, it doesn't, this wasn't important to me because I figured well, you know, I had it in my mind that it was because I took the estrogen replacement therapy that this is the reason it came and since I'm not taking it, it's not going to come back."

Even though she does not think her breast cancer will recur she talks about cancer in general.

"I suppose as the population gets older the risk of cancer is greater but everybody is in the same boat. I don't think, I mean I suppose if it's in your family there's nothing you can do about it. And I believe all the relatives of my mother in Scotland, those that, they all died, umm, they've all died elderly and they all died of some kind of cancer. So, umm, we have to die sometime I guess."

There were two participants who said their cancer would not recur because their treatment was successful. In both cases the participants had had bilateral mastectomies. The first, Catherine, had found the lump in her breast herself. She had a biopsy and an auxiliary dissection. Twenty out of 40 lymph nodes were affected and she elected to have a mastectomy with adjuvant chemotherapy. After her treatment was completed she was
continually finding lumps in her remaining breast.

"And they [the mammography clinic] kept calling me back, you know. . . Well I was really paranoid, you know, and I was really getting worried so I went in and saw the doctor and had this one removed, but it wasn't, the lumps weren't cancerous. But I'm very glad to, I'd rather have none than one, you know, I really would. I really, I felt a hundred percent, I felt like a freak before, you know, I was so happy to have them both removed.

And then when I had the operation he said well, you know, your breast came back that there was no cancer, and like I was quite sure there was, but now I'm sure I won't have to have, I won't have breast cancer. So I've eliminated that.

About four months before the interview Catherine was diagnosed with osteoarthritis in both knees and shoulders, which was causing her a great deal of discomfort.

"It [arthritis] hasn't done a great deal of getting better since September, but I'm hoping it will. The winter's always the worst they say. And if it's only arthritis and it's not, you know, cancer or something, I can live with that, it won't kill me, arthritis won't kill you. As long as I don't get too crippled up I'll be fine.

And, ah, well my doctor said I had a good attitude on it and I would probably beat it and I think, I just feel, I just feel that I'm cured from the cancer, you know. I may not be, but I feel I am. I look at it that way. I could go outside [and get hit] by a truck or something tomorrow, you know. And as far as I'm concerned I'm through, that's over and done with and should it hit again, umm, I'll just have to deal with it again."

The second participant who sees her cancer as successfully treated, also with a bilateral mastectomy, is Leslie. She was also included in the section where breast cancer is seen as a point of change. She was the participant who had been to Mexico on a cleansing program and was now on a special diet. She had been diagnosed with breast cancer and had a mastectomy and
radiation. One year later she had her other breast removed because there was a malignant tumor in it.

"Well I, I strongly believe in the mammogram. Oh yes, who knows what this would have been for me if, you know. Yeah, I had a lump I could feel that, but sometimes the lump isn’t always, ah, malignant. It could be benign and then you go on get yourself always cut into, getting lumps out. I had enough of that, you know, I’ve always had these biopsies done. But you know, you come to the point well, let’s get rid of it. And now I don’t have to worry anymore hopefully (laughs). Hopefully. But if you have cystic breasts it’s a nuisance, you know, ‘cause you never know will it be the real thing or will it, you know, or is it benign?"

When asked if she ever thought about the cancer coming back she replied that,

"I’ve never thought about it but there is always a chance it could. But I don’t want to think, I always keep my mind occupied, and busy, and I’ve go too many things on my mind to be worrying about that (laughs). Don’t worry because that’s a bad thing to do. . . I completely wiped it from my mind because, ah, I’ve had enough of it (laughter). I had enough, I had my share. Yeah. Just wish that more people could think about it like I do. But you can’t tell anybody what they should do. But anyway it worked for me."

In these two cases the participants have reduced their personal risk of getting a recurrence of the cancer because they have had both breasts removed.

Constructing breast cancer as an acute illness relegates the experience of having cancer to an ordinary, or at least not extraordinary, experience. It becomes just another surgery, just another illness. Life after this illness returns to normal, usually busy and active. There is little concern about recurrence of the cancer because the cause has been eliminated or controlled.

This construction is very different from the two accounts
presented in Chapter V. It is tempting to label these participants as denying that they have had, or may still have, cancer. However, their stories are coherent and rational, and talk explicitly about being diagnosed with cancer and the difficulties of going through treatment. This schema provides these participants with a sense of closure or termination of the illness process, and a framework for continuing with day to day life.

What I find of particular interest is that this construction of breast cancer as a discrete entity with specific cause and successful treatment is a way of eliminating the uncertainty of having cancer. This construction reformulates the discourse of hope the participants learned during the diagnosis and treatment, but not significantly. The schema does not include much beyond the cancer itself and treatments. The participants do not incorporate their personal lives into the discourse.

D. Breast Cancer as a Terminal Illness.

The stories using this schema construct breast cancer as a terminal and life-threatening illness, much like Rebecca. Besides Rebecca there were four other participants who used this schema.

In these accounts the breast cancer brings the participants face to face with their own mortality, like those whose stories focus on breast cancer as a point of change. However, these stories include the possibility of death as an end point. They are much like Rebecca talking to her son and husband about the
possibility of her death. It is not that any of the participants have any wish to die, but all seem comfortable with discussing the possibility of their own death and the effect it might have on their family.

These accounts are similar to the group of accounts that focus on the cancer as a point of change. There is the construction of a personal risk or predisposition to getting cancer, using many of the same risk factors. In most cases part of this personal predisposition is the description of cancer as an entity that is present in a minute or dormant form in all people awaiting a trigger to start it growing. For example, one participant who worked in a hospital said that getting hit and pinched in the chest at work may have triggered her breast cancer.

Even once the cancer has been treated it may still be present in the body, and all that may be needed would be another trigger to start it growing again. If the cancer recurs it would be worse the second time. It may have spread to other areas of the body, particularly the bones, that cannot be as successfully treated.

When Laura was asked why she would not say that she was "cured" she responded,

"Well I always think that you should never, if you want to use it, tempt the gods (laughter) because they're going to let you have it (laughter). And, ah, I don't ever think you can ever say that you're cured of anything because if there is a, umm, especially with cancer, umm, if you want to use the word 'seed' which I will use, if there is a seed in there once, what's to prevent another one from appearing. And, ah, I don't say it will, but I'm not going to say that it won't."
When asked if she thought much about the possibility of getting cancer again she replied,

"I don’t, I don’t, umm, say I’m cured but I also don’t think, you know, say well gee I’m going to sit here and mope, and say, and wring my hands and say well gee it’s happened once, it could happen again. I mean that’s stupid, you have to go on with living."

Sandra stated that "The thing is, I know, I’ve had cancer once, I’m going to have it again." Later when the interviewer asked her why she said that, she responded,

"Well, because I had, I’ve always had this feeling that, maybe I’m wrong, everybody has cancer, everybody does, but what starts it off in some people and not others we don’t know. But I do know that once you have it, have had it, you’re going to get it again, somewhere along the line."

A third participant, Leanne, related that she had had surgery on her breast 40 years ago after having bleeding from the nipple after the birth of her son. She is suspicious that this may have been a cancer, and that it just returned 40 years later. Looking to the future she says,

"I mean, we just all think it’s wonderful and just think, glad that we, you know, we got through it and everything’s fine. And you just, ah, hope it stays that way for, you know, and if they stick to the, umm, what do they say the statistics claim, you know, fifteen to twenty years. So if it stays like that your chances of getting it back are in that area, then fine we’ve got nothing to worry (laughter). Oh, we’ve got nothing to worry about, not when we’re in the 70 bracket, you know, because, ah, I mean the law of averages says your life, I mean you can go to 82, 85. You know that’s, I mean that’s plenty to be on this earth really, you know."

A fourth participant, Robin, whose narrative was also included in the section on breast cancer as a point of change, talked about the possibility of the cancer recurring. She was the participant who attributed her cancer to her consumption of
artificial sweeteners and other chemical food additives. At the end of the interview she talked about selling off everything, buying a boat and going sailing, and "forgetting about everything". When asked if she thinks about dying she replied,

"'Cause a lot of women do get it back, you know. It's true, I could get it in the other breast and I could fight it again for another seven years. I mean if it's confined to the breast and a couple of nodes, I mean you could probably go on like this for twenty years, maybe. But once it goes to the other parts, it's over, and I would never take treatment if it got into my lungs or my bones."

I: "You wouldn't?"

"No, because I've had people, umm, a friend that has died of lung cancer and he took all the treatments and everything, and I've had a friend that died of brain cancer. . . . Basically you're going to die anyway. Well, if you have lung cancer or bone cancer you're not, or liver cancer, you're not going to be around for that long. So no I wouldn't take, if it was the breast again, I would do it but any other parts of the body I would not do it.

No, it was the last time when I went for all my bone scans and they found hot spots and I was so sick, I was actually in bed for a good week. I talked to my doctor and he said, 'Well, we want you to go for a bone marrow.' And I said, 'No, I'm not going to do that.' I said, 'If it's in the bone, be honest, it's really bad isn't it?' And he said, 'Yes, it is.' So he said, 'I'll give you some pain killers for now and we'll see.' And ah, so you know, I stayed in bed, my sister looked after me and then this one day I got up. I felt better and I couldn't, I mean, I still have all the pain and everything, but not everyday. Like some, like today, I have them, yesterday I had them, but last week I was fine and, umm, and that's when I discussed with my doctor if it's in the bone I'm not, I'm not taking any treatments. And I told my husband and he said, 'Well, it's up to you, I really can't force you into taking, you know, all those treatments again.' I said, 'No, I don't want to.' So, that's what I'm, when I was so sick there I knew I wouldn't."

One common characteristic of the participants who use this schema in their stories is that they are comfortable talking
about their own mortality. They construct an account of life that has an end point in their own death. These participants tend to be older and have faced experiences, such as Rebecca's diagnosis of Parkinson's, that have brought them to tell their life story with an ending. For most the recurrence and possible spread of their cancer plays a role in the end of their life story.

With this schema the return of the cancer, and the end of the participants' lives, is inevitable. However the important thing for the participants is that they not dwell on it. This is accomplished through having a positive attitude, having faith, and keeping busy. The participants invoke what I have called "the rhetoric of dealing with adversity", which will be discussed in Chapter VIII.

This schema again includes a modification of the discourse on hope learned during the process of diagnosis and treatment. The focus of the discourse is not on trying to prevent the illness from recurring, but on making the most of the time that remains. Cancer is not constructed as being survivable, but the death sentence is one that can be delayed.

By constructing their stories with an end point in their deaths, the participants are also removing some of the uncertainty of having cancer and creating a sense of certainty for the future.
E. Constructing Breast Cancer as a Part of Life.

The participants using this schema construct stories where their diagnosis of breast cancer is an event, possibly an extraordinary event, in a life that is full of similar events. There were eleven participants who used this schema.

For these participants breast cancer is no more significant than other events or health problems. The diagnosis and treatment of breast cancer is not seen as a point of change, although other events such as the death or illness of a spouse are. After a diagnosis of cancer the participants describe their lives as either having returned to normal or having changed as result of other events.

In telling the story of breast cancer as part of their lives these participants construct the cause of their breast cancer in much the same way as the other participants discussed previously. They develop an account of personal risk, including many of the same risk factors such as family history of cancer, pollution, diet, age and past health history. They include the construct of the precursor of cancer which is present in everyone. And, like the other participants, they include the concept of a trigger that started the tumour growing. The triggers include both injury and stress.

What is distinctive in this schema is an intricate link between the cancer and the participants' history of other health problems, some of them ongoing. The following are some examples that demonstrate how some of the participants construct their personal risk of cancer and how their stories integrate their
diagnosis of treatment into their personal histories of declining health as they age.

Karen, who was 63 at the time of diagnosis, explained that she had had a mammogram a few months before she was diagnosed and nothing abnormal had been detected.

"It just, it's almost like the mammogram missed it or something. ... Because, you know, I, he said to me, he said, 'No, cancer takes awhile unless you had an accident.' It would have been there when they took the mammogram.

Well, I'll tell you one problem I, I didn't go through the change of life until I was 58 or you know, my menstruation didn't stop 'til then. And so I had been going to the gynaecologist and I had a lot of estrogen in my system. And the gynaecologist that I had at that time said, 'Well, that's fine.' A lot of fat on my body and they claim fat makes estrogen. He said, 'It will be easier on you for the change.' Well when I had the, when they discovered the cancer in my breast, it was caused from estrogen, too much estrogen."

She described what she felt like when she was first diagnosed with breast cancer.

"When you hear that terrible word cancer, at first you know your heart just sinks, but then you think, 'Well, I'm not going to let it beat me.' Well I know I'm going to die one day, but not at that time."

She had a mastectomy and was on tamoxifen for three years. Six months after her mastectomy she decided to have the other breast removed, because having only one breast was extremely uncomfortable. Now she and her husband "lead a quiet life". As far as she is concerned, "you know, cancer of the breast seems so mild, if you catch it in time, that's the big thing."

A year before the interview Karen had had some problems with vaginal bleeding.

"And I had it, of course I went to the doctor's and he sent me to the gynaecologist and, ah, but the
end of December I had it constantly. 'Til March and then they took me in for day surgery and removed a polyp from the uterus. Now I asked the doctors at the time, 'Do you think the tamoxifen could have anything to do with it?' And they wouldn't comment, you know, naturally, but what happened was when I went in before the operation for the ultrasound, the operator commented, she said, 'This is a side effect of tamoxifen.'

And then in September my husband and I were just getting ready to go on a, on a cruise to Hawai'i. And, umm, they discovered I had diabetes . . . It's type two, its just the, umm, a lot of elderly people, the doctor felt maybe it was a result of the shock my body had been through."

Lisa, who is blind and was in her eighties at the time of the interview, expressed concern that she would lose her independence. She lives on her own, with some assistance from friends. She has to depend on public transportation or on getting a ride with friends. She also has arthritis in both knees, which makes walking difficult even with a walker. Over the past decade she has fallen twice, breaking her hip and slipping a spinal disc. Talking about her back problem she said, "Finally they put me in the hospital and they took the disc out. They didn't put anything in to stop the vertebrae from going together. . . And they're degenerating so I have to be careful because they could easily go into the spine. So there's that, I think that's (laughter) I think that's about all, but you see what I mean about keeping my independence as long as I can too."

Lisa spent much of the interview discussing her problems finding help to assist her in transportation and with housework. Her sister helps out, but she has her own health problems and looks after an ill husband. During the interview Lisa talked about two younger men, one of whom she had worked with before she retired, who help by driving her to doctor's appointments,
cooking some meals and going with her to bingo games and other events. However, over the past few years her activities have decreased due to the loss of her sight and lack of mobility.

"And so mother and I both joined the Ladies Auxiliary [of the Legion] but now that my eyes are, I was their secretary for three years, but now that my eyes are gone, you know, I, I just can’t get up there all the time to the meetings and that, so I, and I can’t do anything to help them. You know, so I just withdrew from it. And it, it meant getting the Handi Dart in the afternoon and then a pick up late at night and, ah, so I just didn’t bother... I miss seeing all the people, you know, but, ah, and then there’s things I just cannot do. For them. And, ah, to me joining and not doing anything is not very nice. You know if you join one of these things you should be able to get in and help. And, ah, of course I still belonged when I, ah, had the breast operation. But it was my eyes that caused me to quit."

I: "So it almost sounds like in the things that you’ve gone through with your health problems that the breast cancer was really not one of the serious ones."

"No, it, it’s routine. Something had to happen (laughter). It was just a case of something else happening (laughter). Just the same as I got this cold and now I can’t get rid of it."

These are stories of aging, and breast cancer as a part of aging and the failing health which comes with it.

There were other stories of changes produced by an aging and retired spouse. There was Heather, who was concerned about her husband’s retirement and his diagnosis of lung cancer. She found the lump in her breast herself just as her husband was coming out of the hospital after having a lung removed due to lung cancer.

When I said it must have been difficult having her husband just home from hospital she replied,

"Well, I didn’t even compare the two, cause, umm, 113 Handi Dart is a special transportation service for the elderly and handicapped offered by British Columbia Transit.
maybe because I worried about him. You know, there was other things in my mind, and when the girls [her daughters] came in for a little while to see me I would say, 'How's dad?' and 'Oh, he's fine.' And you know, this kind of thing. I was sitting up watching television and laughing at the silly things on TV, you know. So he was sick. Mind you his was much, much bigger."

In the interview she said that five years before her diagnosis of breast cancer she had been diagnosed with ovarian cancer and had to have surgery.

"And I asked Dr. Simon, you know, would it [breast cancer] have anything to do with the other [ovarian cancer] and he said, 'No, no, they're not related at all.'

Because, because I used to hear, see that was my first experience, ovarian, and, ah, they said if five years passed then you’re free. Umm, and then five years and this popped up. So I thought, 'Oh darn, you just barely think you’re in the clear and you’re not.'

But then when Dr. Simon said, 'No, they’re not connected at all.' And he explained it to me, he said, 'As you’re getting older things are going to happen, you know, umm, like you get arthritis or your, your kidneys aren’t functioning perfectly. You’re, you know, you’re getting older, everything is kind of wearing out.' He said, 'That’s just one of those things.' Something, you know, some little thing will pop up. So, so if I keep myself active and busy, I figure well the old body might last a bit longer (laughter)."

When asked if the cancer had changed her life, Heather replied that her life hadn’t changed. Then she explained that her husband never returned to work after his diagnosis of lung cancer because he would have been 65 a few months later. She said, "Umm, the retirement, I guess that made a big change." I asked her to tell me about those changes.

"It’s still bothering me, and that’s wrong, umm. He turned 68, yeah, so that’s three years and I still, 114 Dr. Simon is a pseudonym.
I just resent having somebody in the house constantly, you know. All day long, somebody there that will, umm, I have to say, 'Well I'm going to go up the street now, is there anything you want before I go? Do you want me to bring you back something?' And when he was working I just went up to the store. I miss that. . . But, umm, I don't know it's, it's harder for me to get away and do my own thing with him in the house. You have to think, 'Well, you know, it's not fair to love him and leave him all the time.'"

There were two other participants who were caring for sick spouses at the time of the interview, and for both that was the most important thing in their lives. In one case Laura's spouse had had a serious stroke six months after she completed her treatment for breast cancer. The interview took place six months after her husband's stroke and he had just returned home from a rehabilitation facility. Reflecting on her experience of being diagnosed with breast cancer and then caring for her husband Laura said,

"And also when I was talking to my specialist, umm, my surgeon, umm, I had just said to her, you know, well the first thing you feel I think is 'Oh God, you know, this is it. I've had it.' And then I thought, 'Why me?' and then I thought, 'Oh my God, why not me?' You know, what makes me special (laughs). And you've got to go along like this, and besides this isn't going to affect you that much, you carry on with your life as, and you know, put it behind you. I could come up and you're well aware of the fact that it can reoccur, but you do not, I think if you're smart, you don't dwell on it, and go on with your living so half the time I forget about it and go on with what I have to do.

Yeah, and then when you get out there and you see all this, there was a little toddler about this big, and you know, you think 'My God I've lived my life, this little kid hasn't begun to live and, you know, she's in there obviously because she has cancer of some form, and that's when it makes you feel like I've been lucky. And, and especially when you go and, ah, now especially when it's brought home to me with the, ah, my husband."
The second participant caring for a sick spouse was Eileen, whose husband was on a waiting list for heart bypass surgery. She was very concerned about her husband and very frustrated with having to wait so long for the surgery.

"Oh, of course. It’s having an influence on our whole family. Oh, absolutely. Having to wait. You can’t make any plans, he’s told to be a couch potato. Somebody who again, you know, has had a, well had a natural business life and a very active volunteer life to be told to be a couch potato is very difficult."

Eileen compared her own experience with breast cancer and how quickly everything happened to her husband’s experience of having to wait for his surgery.

"Ah, that was it, it was all done very quickly. So I think that was excellent, I feel very sorry for people who have to sit around and wait. And to give you an example of that, my husband is waiting right now for bypass surgery, and I feel very sorry for him because he has no date. So, umm, the quickness of looking after my situation I think was very helpful and if everybody could be helped that way I think it would be very, very beneficial."

Two participants in the study had become widows around the time they were diagnosed with breast cancer. Both had been nursing very ill spouses and felt the stress caused by their husbands illnesses triggered their cancer. Christine said,

"And I think I had been so upset with my husband’s illness that I was really unaware of what was happening to my body. Just so stressed out. . . And so it was about this time that his health had been poor what the diagnosis was that it was cancer. And, umm, when I found this out I just sat in my car, under the tree there by the hospital, they were all in bloom, it was in the spring and the beautiful pink blossoms, and I thought how can I ever cope with cancer and my husband’s illness."

The deaths of these participants’ spouses and the diagnosis of cancer were a very "black time" in their lives. Both
participants described how their lives have since improved. Both now feel their lives are getting back to normal, but are very different from before their husbands' deaths.

Christine said that "I'm just, sort of, like a different person." Very little of the improvement or change is attributed to the breast cancer, but rather to beginning a new life after the death of their spouse.

Stephanie explained,

"But like I say as I look back it was a good, because, I lost my husband and, umm, I was just getting over that when, so it was quite a down period for me. I had just lost my husband two years before that. And, ah, then to have two, two years of this cancer bit, that was, my husband was sick for a long time too, so I've gone through a lot."

When asked her what helped her to get through all of this Stephanie said she "acted".

"Well the day that I found out that he was not going to make it, they, the doctors and nurses met me in the hallway, I'm on, I'm on the way into the room to see him and that was, you know, so just like that, between the time I left them in the hallway until I flipped the lights in my mobile home here I had a smile on my face. I'd go bouncing in and say to him, 'Hi there, how you doing today?' If that's not acting, what is it called? You just have to do it.

Now I'm happier, this acting business really worked for me because I became more independent, umm, there's a couple of people call me happy go lucky 'cause I've always got a smile on my face. They didn't know that, that smile wasn't there all the time, but it got to be more often. I'm a different, different person altogether than I was before my cancer and I think it's because it was such a blow that I, you've got to take everyday as it come and make that best of it. And now I'd say I was, my life has completely turned around and I, with my gentleman friend and I tell my friends that life is just nothing but a bowl of cherries right now, thank you very much."
Most of the participants who use this schema in their stories are older, over the age of fifty. However, there was one younger participant who also used this schema.

What these participants have in common is how they relate the cancer to other experiences in their lives. The older women talk about experiences, such as episodes of their own or a close family member's poor health, that required they continue on with everyday life once they completed their treatment for breast cancer.

The story of the one younger participant in this group, Denise, demonstrates how a series of very different experiences, including being left by her husband, are developed into a very similar account.

Denise constructed her story by first eliminating many of the risk factors commonly associated with breast cancer.

"And apparently from what I was told at the Cancer Clinic, lobular hits older people moreso than younger people. And I thought again, what did I do wrong? I had my children at the proper age according [to] statistics. Breast fed them. I was never a fat, obese person, I was always an energetic person. I'm not a big consumer of fat, hey I like my greasy burger like anybody else, but, you know, I don't live for McDonalds. I love fruit and vegetables. I've always been active.

I think my own children were afraid to hurt me, afraid to get me to cry. See, because we had just gone through an extremely traumatic thing in this house. Some people say cancer and stress are related. I'm starting to think possibly, see because in June, I had been married for 18 years and we had a wonderful relationship, excellent relationship. . . One day after I'd come home we went out to the backyard to have a cup of coffee, and he looked at me and he said, 'I don't love you. I don't love my kids. I don't want the house. I don't want anything. I'm leaving.' And with that, he had his suitcase packed, and he walked. So
none of us were prepared for it... And see, we were basically just getting over that and then bang, the cancer."

It was September when Denise found a lump in her breast. She went to her family doctor, who sent her for a mammogram. The mammogram came back negative. So her family doctor decided to send her to a surgeon.

"Right and I waited, I don't know ten days approximately to get in to see the surgeon. Went to him, he palpated and he said, 'Well, we'll have to remove this.' So you wait again so you can get into the day surgery at the hospital, so I waited for that. I went in he did it under a local and he said to me he could see, he thought, another lump further down, but he couldn't get it. He did not want to dig that far. So he removed the lump and wouldn't say anything and I came home and I guess it was not that, the next day but it was the day after my family doctor phoned me and said that he had had a lot of thought and debated what he would do and he decided that he would phone me at home and let me know that it was malignant rather than me driving down there on my own. Because I was then a single mum.

Then it was a case of waiting to get back to the surgeon to discuss options. So again let's wait for an appointment. Then he gave me my options and my choice was to have a modified mastectomy, modified radical. Basically because it was lobular, because of my age, 'cause my kids didn't have a dad around. Umm, and if I chose the lumpectomy then you could have the option of going lumpectomy and radiation, or whatever. And, you know, my thing was get rid of it, get rid of, who wants half a breast. Right. And it was very fortunate because after I had the mastectomy they found four other lumps in the breast. So that really makes me happy because I have a girlfriend that opted for a lumpectomy and she's now dead."

The surgeon referred Denise to the British Columbia Cancer Agency. At the Cancer Agency she attended a breast conference where a group of professionals got together to discuss her case and then came back to her with recommendations.

"And they came in and they informed me that I had, again, don't quote me on numbers, but I think they said a 30 to 35 % chance of developing cancer in the other
breast. Because it was lobular and the way they explained it to me, it's like a tumour with a runner. And the minute I heard that and their recommendation was not to have the breast off right away, but that was not my goal. My goal was I want it done, I want it out of there, if they would have said zero percent chance of developing it, fine. Even if it was a five or a ten, but I thought no, I couldn't live with that. So I went to the surgeon, told him about the breast conference and my percentage and he said, 'What do you want to do?' I told him I want to get rid of her. And I went in two days later and had the right breast off."

At the time Denise was going through her diagnosis and treatment she was caring for four foster children and three of her own.

"It is and like I said my focus was not cancer. That wasn't, my thing was the kids, the kids. And Human Resources had offered to take the foster children that were in care here at the time with me away. And I said, ‘No, they’re what, they’re going to drive me, they’re going to make me thrive just as my own kids are. They’re my goal for living, don’t do that.’ And it’s an education for them, you know, I wanted [them] to basically think here you can have breast cancer and you can beat it and I’ll be the example for that. So they didn’t remove the kids, they kept them here."

At the time of the interview she considers her life and health back to normal after having had a diagnosis and treatment for breast cancer. When asked if she had ever attended a support group for women who have had a diagnosis of breast cancer she said,

"They offered it to me but, (a) it was all the way in Vancouver, (b) I felt that I had accepted it. I didn’t have, you know, I guess it’s like a, losing a limb, you know, you have to go through your little stages whether you lost your arm, or if you lost your leg, because that is a significant part of a female, the breast. Right, but that was never my big, my big thing, mine was to live for my kids. That was, and I

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115 "Human Resources" refers to the Provincial Ministry of Social Services and Housing, responsible for foster care of children in British Columbia.
didn't really feel that I needed a support group, like I have a really good bunch of close friends that if you wanted to talk to them or whatever they were there for you. My family doctor is also extremely good. So I didn't, I didn't feel that I needed, and I know, I guess support groups you hear them whine and complain and carry on. No, no like smarten up, it's gone, accept it, get on with your life. I couldn't handle something like that, but that's me."

When asked if it was important for her just to accept that she had the cancer and get on with her life she replied,

"Yeah, yeah for my kids. For my kids that was, look guys I teach you that cancer can be beaten, you know, it doesn't matter what part they take of you, you still can get on with it and, you know, that was really important to me. Because they're, you know, the T.V. programs that are out that kids see usually they die. Usually they die, they don't make it. Like it's a nice, beautiful movie but the end they're gone and I sure wish that they would make some movies where they've beaten it."

Denise constructed her breast cancer as being over with, although well aware that it may recur. Her reason for wanting to "get over" the cancer was as to continue care for her children. Constructing their stories this way is a way of putting the uncertainty of breast cancer "behind you", and allowing the participants to continue on with caring for others or rebuilding their own life after another traumatic change.

One way of putting breast cancer behind you, and so of creating some certainty and hope for the future, is to talk about the disease as "not being that bad" or as not being as bad as other illnesses or problems. Many of the participants in this group did this through explicit comparisons to other people with more serious health problems, such a spouse with lung cancer or stroke. Once again this is a modification of the discourse of hope learned when going through diagnosis and treatment.
These stories not only represent the construction of hope, but also the response of women having to live their everyday lives being primary care-givers for sick family members and dealing with a multiplicity of health problems related to their own aging. They are a reflection of living day to day with adversity. Much of the adversity is created not by specific health problems but with being an older woman in Canadian society.

F. Miscellaneous.

There were three stories that do not fit clearly into these schemata. They are interesting enough to discuss separately. Each of these stories shares something with at least one of the schema, but each also tells a story which is unique and raises interesting issues about the cultural construction of breast cancer.

The first story is that of a young woman. Angela was in her mid-twenties when she was diagnosed with breast cancer. During the interview it became apparent that her age provided a different context for her experience with breast cancer. Being younger she had no personal experience with breast cancer. Neither did any of her peer group. She was also treated slightly differently by the doctors and oncologists due to their biomedical understanding of the rarity of breast cancer occurring in someone her age.

"Well one thing that did concern me when I first was diagnosed is, is that, that the doctor said that I didn’t fit into any of the, umm, categories and shouldn’t have this disease. And I kind of wondered about, maybe they should be searching for other reasons
why women get breast cancer. Cause I read apparently most people don’t fit into those categories, and it doesn’t make sense to me, so I guess that’s the only concern that I had. I have a concern about how maybe, maybe the doctors go by the book too much. . . Yeah, umm, yeah they said that, umm, most people at my age that do, ah, get breast cancer are usually obese, or else their mother has had breast cancer before."

The doctors talked about her not fitting into their risk categories, but as Angela talked about what she thought caused her breast cancer she, like many others, developed her own personal predisposition.

"Well, umm I thought maybe an injury, I thought maybe that, I remember one time, ah, I was grabbed by the breast one time and they squeezed it really hard and I thought well maybe the injury, or, umm, what else. Well I wondered, well I’ve had, umm, a couple of abortions when I was younger and I thought well maybe the calcification, through that some strange calcification occurs through that, I don’t know.

So I, so I, that’s one thing that, I guess it’s affected me is I wonder what caused it sort of thing. . . Not, not often but, but every once in awhile I’ll think of something that my have cause it and I’ll wonder if maybe there’s higher breast cancer in our neighbourhood, in, in, Edmonton. And I’ll wonder well, maybe there’s some strange thing going on around there, maybe there’s radiation coming from somewhere around there. Or maybe it was the x-rays that I had on my foot when I was a kid. So I don’t know, I think of different, all different reasons why I could have gotten it."

During the interview Angela mentioned a number of times she had no idea how bad the treatment was going to be. She had chemotherapy, a mastectomy and radiation therapy.

"Well at first I, ah, I kind of thought it would be interesting to go through it, you know, I just didn’t really think it was going to be as bad as it was going to be. . . And I didn’t, I hadn’t expected, umm, the reaction, I didn’t expect myself to go through what I went through I thought it wasn’t going to be as bad as it was."

Because Angela and her friends and acquaintances had no
experience with cancer or the treatment for cancer her access to
information and support was restricted, unlike older women who
knew someone who had had a diagnosis of cancer. She explained
that she had been too insecure to approach a volunteer or join a
support group.

"And I didn’t, I was too shy to actually go and
get the counselling. . . They send out their
volunteers, umm, that would come over and tell you all
about it before you went for your treatment and say,
'Well if you need any help then call us.' I was sort
of way too shy in calling that person. I thought they
wouldn’t want to speak to me, and felt quite often that
people wouldn’t, weren’t interested in talking to me.
Umm, I was, I think it was because I was very weak and
by the, by the end of this I was very weak, and
paranoid, and felt that people weren’t interested in
talking to me and, umm, I think I’ve gotten over that
now, I’m not so, as self-conscious. . . I think, I
would walk around at school, down the hallways like,
like, oh everyone knows and, umm, or why is that person
looking at me that way or things like that, and I don’t
think I do that anymore. I think I’m more goal
oriented, now in my head. Than I am people oriented,
like worrying about what people are thinking."

Angela took leave from college as she went through
treatment. Going back to college afterward she worked hard and
got better marks at school than before her diagnosis, which she
felt helped her get a good job. Angela worked so hard because
she felt she needed to prove that she did not need other people’s
pity.

At the time of the interview over five years had passed
since her diagnosis and treatment.

"Umm, I’ve just gone back for, every six months to
the Cancer Clinic, umm, just had x-rays and mammograms
and that’s it, and blood tests and I get regular check-
ups. There hasn’t been any reoccurrence. Umm, yeah
that’s all I’ve been through is just the regular check-
ups and they discharged me just recently. . . Oh, it
feels good (laughter) it’s quite a weight off my
shoulders, that’s for sure. Yeah, now I feel like I’m
almost completely over it now, it seems so. Time’s
gone by, and five years has gone by and, and I'm reconstructed, and everything, and so it seems almost back to normal."

Being young, single and having had breast cancer treated by a mastectomy affected Angela's image of herself. Losing her breast and all her hair during chemotherapy made her feel unattractive, as well as insecure. Angela did not attempt to start any relationships with men until she had had reconstructive surgery two years after she completed her treatment.

But it was not only these feelings that made trying to start new a relationship difficult.

"An issue in the relationship, but I remember, at one time it was an issue of reoccurrence, like I would think, 'Well if I get into a relationship what happens if it reoccurs?' And you know, I have to go through all this again and drag, you know, this poor person in, through all this awfulness. And, ah, so that's another thing that kept me from, umm starting up new relationships."

In many ways this Angela's is similar to some of the others. The major difference is the impact of Angela's age. Being younger meant that she had not faced a threat to her life before. Much of the story was talking about how the diagnosis and treatment affected a life that was not secure in terms of being in a stable relationship, having a job or career, or having friends or acquaintances who could link her into information and support networks. She talked about returning to a point at which she could develop some security in her life and continue on a life course more normal for and individual of her age. Even

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116 For further development of the differences in the experience of breast cancer related to age see Waxler-Morrison et al (n.d.).
though it has been over five years since she was diagnosed Angela is still working on repairing her life biography. She is still working on modifying the discourse on hope to fit her own personal circumstances.

The second miscellaneous story is Andrea's. She was in her mid-fifties when she was diagnosed with breast cancer. Andrea was angry about her cancer diagnosis, as she felt she should never have gotten cancer. Her construction of breast cancer has a moral quality, she feels that cancer should not happen to those who have worked hard all their lives.

When talking about what may have caused her disease she said,

"See, my health always used to be so good, like even one of the girls said at work, she kind of chuckled one day and says, 'You know, the way you eat Andrea you should never have had that happen, that happen to you like.' You know, 'cause I eat fruit and I eat a lot of vegetables. Cause I don't take a sandwich to work, I take salads and apples and stuff and yet, umm, I guess it doesn't matter what you do. If you're going to get it, you're going to get it and yet in my family, like my own family, my sisters, there's eight of us, eight girls. My mother's family there was seven girls and nobody had it that I know of."

Andrea said that her family would not talk about the cancer and she was not sure why, which she found very distressing. Andrea told the story of how her family had been through many difficulties. In particular she talked about one of her daughters who "acted out" as a teenager, and was still causing many problems for the family. She said that this daughter was, "very, very difficult and I guess, and I can see why I had cancer, I had a lot of stress with her."

"Yeah, so I really, really was, really angry when
I got the cancer and I think it was because of, and I think it was because when I think, I worked hard to keep my children off welfare. After my husband and I split up I went to work in a nursing home, it wasn't and easy place at the time to work . . . I worked for my kids not to be on welfare and then this one chooses to go out and, and makes a mockery out of it. Sits at the table at Christmas time and tells us she's having her second child. And that husband of my daughter's [older daughter] I thought he was going to have a fit 'cause he's from the old school and he believes in working hard and here she's on welfare, and sitting there, and telling us she's going to have another baby. And I'm having a fit and she's laughing about it. You know, ah, so this is what make me angry was I, I work hard and this is how I was repaid back by having cancer, that's, I always said that was my reward."

The anger and frustration expressed throughout the story was intense. Andrea had always been healthy, she had worked hard to care for her children and therefore did not deserve cancer. It was as if she was suggesting that because she had been faced with so many problems during her life that she should not have had cancer. Breast cancer was equated with other difficult problems, the only difference being that the breast cancer may recur and it may kill her.

"So what do I, actually the best thing happened to me was to go back to work. Yeah I went to, 'cause see I couldn't get the surgery out of my mind 'cause that [arm] hurt all the time so I had a reminder all the time. And I'd go do something, go to wash a window, my arm was sore. I'd do too much, I'd have a swollen arm at the end of the day . . . Ah, well when I went in my mind went on the patients. And my mind wasn't on myself. I never thought of myself."

I: "So that was, that helped?"

"Yeah, yeah 'cause it was a constant reminder like after I come home I would say, 'Well what's the sense of doing this, I'm not going to be around much longer anyway.' That was my attitude. Oh, the attitude was bad, it was worse than having the surgery. Actually I think it's still bad, but, no, yeah, 'cause I cover it up a lot now. And it's, it's got, you know, it's long enough now, sort of forgotten, up until, you know, and then the time come for me to go and have another
mammogram and until I find out that's okay, things start all over."

Breast cancer was interpreted as a punishment that she did not deserve because she had worked hard and honestly all her life. The threat to her life was devastating and it has been very difficult to put that threat behind her, to get life back to normal.

This is a very different story than those of women who have gone through difficult experiences as well as the breast cancer and told the story of breast cancer being just another part of their life. It is as if the cancer is something that happens to amoral or weak people, that the disease is part of a punishment or a flaw in personality or way of living. Rather than trying to deal with the uncertainty of whether the breast cancer will return, she seems to be talking about the uncertainty of the meaning of getting the breast cancer itself.

The last miscellaneous story is Mary's. She was in her mid-forties when she was diagnosed with breast cancer. Hers is mainly the story of how after she was diagnosed and treated she became a breast cancer activist and founding member of a local non-profit organization.

There was no discussion about what may have caused her cancer other than a comment that she eats vegetables and takes the skin off her chicken, and is very fit. After outlining the story of her diagnosis (her cancer was found on a screening mammogram) and treatment (lumpectomy and radiation), she told me the story of how she became a breast cancer activist.

Mary was able, after much persuasion and telephone calls, to
make a presentation to the House of Commons Status of Women Sub-committee on Breast Cancer. In the process of preparing and making her presentation she met other women who were breast cancer activists. Less than a year after being diagnosed with breast cancer she and some colleagues formed a non-profit organization and held a large fund raising event. Part of the narrative was why she felt it was necessary for her to become involved.

"Breast cancer is not one person’s issue, it didn’t just happen to me, and, ah, as if you were peeling away layers of an onion, every layer was sort of another fact or piece of information that was coming to my awareness, especially since the Status of Women Sub-Committee there was so much information to absorb that the size of the issue was getting larger, before my eyes it was growing. And it was just growing like crazy, and I thought I had to do something, I had to. I had to do something, so that others, I was in a very privileged position, in you’re looking at the original dinosaur here, I was married twenty-five years to the same guy and I even love him (laughter). And, um, he’s, he’s able to support me and happy to support me especially through all this. The money would be nice but that’s not the issue. So I had breathing room which is a great privilege."

Mary felt that she was in a privileged position not only financially, but also because she had access to the best treatment facilities that were available. Mary explained early in the interview that after her lump was first detected her family doctor moved very quickly because he was a real "advocate". This implies other women whose doctors may not be "advocates" may have to wait longer. As well, she waited a few

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117 In the fall of 1991 the House of Commons Sub-Committee on the Status of Women of the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women did a study of a number of issues surrounding breast cancer and breast implants (Greene 1992).
weeks to see the radiation oncologist her doctor wanted her to see. Again other women may not have access to this type of information about who is the best specialist.

Despite all these advantages Mary felt "underwater" and was concerned that it must be much worse for other women who did not come from her privileged position. She used the example that despite her interest in physical fitness and training she had been unable to find answers about whether or not to continue with her training. Even though she knew how to do research and was able to contact a number of experts, no one could give her an answer because no research had been done in the area. After this experience Mary was frustrated.

She was also taking on the role of activist for her family and her family's future.

"And I, we, they had an evening here [at the Cancer Clinic] with an epidemiologist and I said to him, you know, 'What are my daughter's chances?' And he went through all these studies. And I said, 'That doesn't help me a bit. What do I say to my daughter? I mean in English.' And he'd go on about her chances being double but that really doesn't mean double that statistically this, that and that. So basically it came down to the fact that yes your chances are elevated but not a hell of a lot more, but she must be smart and take care of herself.

So she got it confirmed from both angles. She phoned me a couple of nights ago and asked me to call her back right away because one of her friends father was diagnosed with colon cancer. So all of a sudden I've become the expert (laughs). Actually she's been very, very proud of the activist stance... And I was really moved by that, it was just, ah, she was proud of that, it make me, its a reinforcer again. I'm going to go out and do more because, I mean, I am thinking of her children and her children's children."

One of Mary's concerns is that more money is needed for research on breast cancer. She is interested in assisting in
raising money through fund raising events. She feels there is a need to raise the profile of breast cancer and the awareness of what women can do to prevent the disease.

"So what seemed healthy for me was going out and getting active. Very clearly a win-win situation. I was in an age group that was interesting to the media. You know someone getting breast cancer at age fifty-five or sixty, is pretty ordinary. Someone, unfortunately, yes, at forty-six in the disputed age\textsuperscript{118} gives the media something to hold onto because of our screening program here\textsuperscript{119} . . . But to be willing to speak out is one thing, to be able to speak out is another thing. So I thought that was a place where I could strategically make a difference."

Another of Mary's concerns is to change the way in which breast cancer, and cancer generally, is talked about.

"And I read Susan Sontag's\textsuperscript{120} book and I understood how the language is defeating us in this case. If we start talking about it as survivors, that's the key, one woman in our group goes like this [hands up like hanging onto a cliff edge] whenever the word survivor is mentioned, I hate it. I mean it's just a destructive stupid concept, it's the one that you tend to be using.

I looked in the thesaurus and it seems to be a perfectly valid word, but the connotation around it. There's nothing proactive about it, it's just I've been beaten up and I survived, and that's what, I mean, you have to do that. If you even think about it, . . . you're not going anywhere if you're dead.

\textsuperscript{118} Disputed age refers to the dispute about the effectiveness of screening mammography for women between the ages of 40 and 50. Most research has indicated that the use screening mammography on women over the age of 50 can reduce mortality from breast cancer, but the findings with women between 40 and 50 have been less clear. This dispute entered the popular media with the publication of the Canadian National Breast Screening Study (Miller et al, 1993a, 1993b), which found no reduction in mortality with mammography used on women under 50. There has been a lot of controversy of the validity of the results of the National Breast Screening Study.

\textsuperscript{119} Refers to the Screening Mammography Program of British Columbia.

\textsuperscript{120} Susan Sontag (1978) \textit{Illness as Metaphor}. 
Why do we stop there? We haven’t somehow devised the language so that people would look at this as a conquerable puzzle. And until we do that I think we’ll have a lot of the stigma, a lot of the ‘I’ve got cancer.’ That makes it a closet issue. I mean it’s kind of like dominos, one falling after another. Puts it back in the closet so we don’t talk about it, so it’s shameful, so you don’t go and get yourself checked because God knows you might get this shameful thing, and I don’t know how to unravel that yet. Any ideas?”

This account tells about how having had a diagnosis of breast cancer has changed Mary’s life, in a sense similar to other women who talk about making changes in their life. The main change is that Mary’s life has changed to become a public, rather than a private, experience.

Mary talks in terms of categories that she fit into, such as being in a privileged position and in an age group that is more unusual and therefore of interest to the media. The formation of categories excludes from her account talk about personal feelings, especially about relationships or death.

In a sense the creation of a public narrative is another way of dealing with the uncertainty of having had a diagnosis of breast cancer. The focus of the narrative is on the production of a commodity, the breast cancer activist, and what can be done through this production to make changes in the future.

Making changes is a way of raising hope of the women who have the disease, or may have the disease, that their futures can be changed. This narrative, more than most of the others, is constructing a discourse of hope that is very similar to that described by DelVecchio Good (1991, DelVecchio Good et al 1990) in that it puts forward the possibility of changes being made in
the future that will assist women who have had a diagnosis of breast cancer.

G. Conclusion

This chapter explored how participants integrated their experience of breast cancer into their lives. They account for having had a diagnosis of breast cancer, what may have caused it and how they are dealing with it. What is interesting are the similarities between some of the stories. These provide some insight into the cultural construction of breast cancer.

The majority of the stories have some kind of description of what may have caused the participants' breast cancer. Most list a multiplicity of possible causes. A number question possible causes because the common risk factors do not apply in their case. The important point of these descriptions is that they are an attempt to account for the participants' experience in much the same way as has been found with other chronic conditions (Garro 1992, 1994).

The most commonly mentioned risk factors are family history, age, reproductive history, diet and environmental pollution. These are risk factors that have been found in other research (Salzberger 1976, Gifford 1986, Chavez et al 1995).

There is also a common idea that everyone has a predisposition to cancer and all that is needed is a trigger to start the cancer growing, also a concept found in other research (Balshem 1991, 1993; Cornwall 1984).
The interesting aspect of this research is how these risk factors are incorporated into the illness narratives. The descriptions of cause open up positive possibilities for the future, such as changing one's diet or trying to eliminate stress to prevent the cancer from recurring. They also raise negative possibilities, such as concerns about other members of the family getting breast cancer as described by Mary\textsuperscript{121}. This demonstrates how important the concepts of cause and risk are in the development of illness narratives. They provide a base from which the individual can go beyond the description of getting ill to a point of incorporating the illness into their personal biography.

In this analysis I found four cultural schemata of how women who have had a diagnosis of breast cancer incorporate the illness into their personal biography. The three accounts that did not fit into any of these schemata suggest there are more than four schemata. For example, the narratives constructed by very young women like Angela, may be very different from those of older women (Waxler-Morrison \textit{et al} n.d., Oktay and Walter 1991).

Each schema represents a different way in which the participants are able to fit the illness into their lives. To a degree each schema is a reformulation of the discourse of hope the participants learned during the process of diagnosis and treatment. The reformulation maintains some of the discourse of hope's optimism (Robinson 1990).

"Breast Cancer as a Point of Change" is used mainly by

\textsuperscript{121} This will be discussed further in the next chapter.
younger participants. It is a commonly understood schema, as it is presented in much of the popular literature (for example Landsbury Company 1988, Jillian 1986, Williams 1993) and fits best into our cultural ideals of how individuals should respond to the advent of a chronic illness (Locker and Kaufman 1988, Brodsky 1995, Robinson 1993, Powell-Cope 1995).

The discourse of hope for the future maintains the optimism learned during diagnosis and treatment but is broadened to incorporate many other aspects of day to day living. For many participants use of this schema is empowering, they are doing something about having had a diagnosis of breast cancer. However, this schema does have a negative side, in that if the cancer does recur it leaves the participants open to feeling guilty because they did not do enough to prevent it.

"Breast Cancer as an Acute Illness" is probably the most unusual schema. Its main element is that it constructs the cancer as something ordinary, that can be controlled and treated successfully. In this sense the discourse on hope is the most similar to that learned during diagnosis and treatment. The modifications are minor, only enough to shift the discourse to apply to their particular circumstances. The participants who use this schema are able to accept that biomedicine can successfully treat their cancer, while other participants always have an element of doubt.

The interesting aspect of the "Breast Cancer as a Terminal Illness" schema is the participants' acceptance and willingness to talk about death. This schema is used by mainly older
participants or those, like Rebecca, who have other serious health problems. It is not that these participants are avoiding death, but that they are making the most of the time left (Corbin and Strauss 1987). They reformulate the discourse on hope to focus on making the most of the time left, which changes the content of the discourse significantly while maintaining some of its optimism. The most important point is the reconstruction of the meaning of the passage of time.

"Breast Cancer as a Part of Life" is a schema also used by mainly older participants. In this schema breast cancer is described as being only one of a number of serious problems. The main focus of the schema is the continual minimalizing of the breast cancer by comparing it to other problems. Therefore in this schema the discourse of hope as learned during the diagnosis and treatment is modified to such a degree that the cancer fades into the background. The participants using this schema tell stories of adversity, much of it being related to social and economic circumstances the participants find themselves in. This is a good example of how external socioeconomic circumstances will affect the construction of an illness narrative (Gerhardt 1990, Kaufman 1988b).
Chapter VIII - Breast Cancer as Social Reality

This chapter is an examination of the process by which women who have had a diagnosis of breast cancer incorporate their illness experience into the social reality of their everyday lives. The participants' illness stories describe their interactions within their social world. The stories include descriptions of the work of representing themselves to others, of reactions of family and friends to their diagnosis, and of commentary on the resources available for women who have had a diagnosis of breast cancer.

It is evident that the diagnosis of breast cancer is a disruption of one's social world, and not just a disruption to self and identity. The participants are in constant interaction with other people and situations that affect their day to day experience of living with having had a diagnosis of breast cancer.

The importance of moving the analysis of illness narratives beyond the exploration of reconstruction of self and identity is to allow for the exploration of the social and economic context of chronic illness (Comaroff 1982). The individual constructing an illness account includes descriptions of the limitations imposed by the economic and social context (Kaufman 1988b). Analysis of these limitations provides a framework of understanding the broader context of chronic illness within society.
This analysis is informed by what has been called critical-interpretive medical anthropology (Lock and Scheper-Hughes 1990).

Sickness is not just an isolated event, nor an unfortunate brush with nature. It is a form of communication - the language of the organs - through which nature, society and culture speak simultaneously. The individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity, and struggle. (Scheper-Hughes and Lock 1987:31)

Unlike the story of diagnosis and treatment, the incorporation of illness experience into the social reality of everyday life has no identifiable structure. The description of this process is dispersed throughout the interview.

There are cases where interactions with the social world support the participants' construction of their breast cancer experience, in particular their evolving discourse of hope.

In other cases these interactions challenge both the construction of the breast cancer experience and the discourse of hope. In these cases the challenges are included and accounted for within the story. However, these challenges tend to lend a discordance to the account.

Exploring the interactions with the social world which support and challenge the cultural construction of breast cancer provides insight into important elements of that construction.

Some of the areas that I explore are;

A. Representing Self - "Mine is not as bad as some other people's"

B. Breast Cancer as a Family Experience

C. Breast Cancer and Social Interaction
D. Becoming a Member of the Cancer Community

E. Looking to the Future.

Before exploring these themes I will present two accounts as examples. The first example will be Lynne's description of her family and friends' reactions to her cancer. Lynne's story of diagnosis and treatment was outlined in Chapter VII. Lynne was 43 when she was diagnosed with breast cancer, and was interviewed only one year after her diagnosis. She is married and has one daughter, who is also married. Lynne works full time in the records room at a local hospital.

Part way through the interview Lynne explained how important it was for her to be able to talk about her experience with other people. She started to talk about her family and friends.

"Like, I mean, you can have all your friends around and all your family and you still feel alone sometimes. Especially family, when I first had it, like I just felt so lonely and yet I always had, you know, people around me. But yet it's just the loneliest feeling in the world, like you just feel you're alone no matter how many people you've got around you."

I: "Is it something that you just can't share with them or . . ."

"No, I don’t think so because I mean, like, I never had difficulty talking to them, I mean, like, my aunt and my cousins know my most intimate details about this whole thing but it's just so lonely, lonely feeling. . . you feel like you're all alone in the world and (chuckles) I mean nobody can possibly know how you feel."

I: "Is that hard to just deal with that, that feeling?"

"Umm, it was hard at first, it was difficult and that, but it's, you know, something that just, like, it kind of just went away after, after the treatments and that were done. Like, it was almost a big breath, you
know, it’s over. Not like you’re trying to instill into your mind it is over for good and that’s it. I mean deep down you know that it’s probably not, but you know you try to convince yourself that that’s it, you know, that treatments are over, I’m well now."

Lynne went on to talk about her family. She grew up in Ontario and most of her family still lived there. She had an aunt and two cousins in Vancouver who she was very close to, much closer than her younger sisters.

"In fact I found it easier, like, I mean, I can talk to my cousins about every little intimate detail about my cancer but yet when I went home, like, I had finished my radiation in December and we went home for Christmas last year, but yet nobody would talk to me about it. I mean, so I didn’t want to initiate it I thought if they don’t feel comfortable with talking about it, like, I mean my mum would phone me twice a week all the time I was going through my chemo and that, but yet, you know, she’s, I don’t know, they just couldn’t talk about it. . . I, I guess I, you know, when I got there, well, you know, once I talked to them about it but everybody, maybe because the whole time I was there, there were so many people. . . So maybe, that had something to do with it. But then again I don’t think so ‘cause I just came back from Ontario a couple of weeks ago and they still really don’t talk about it down there, like they still find it difficult to talk to me about it."

I: "What do you think it is?"

"I think that they think, like, ‘cause I have four sisters and I think they’re all thinking, you know, ‘I don’t want to make this real. I don’t want to talk about this, maybe it will happen to me.’ ‘Cause I mean, you know, you hear all these things, your sisters, you know, if you have it your sisters have to be careful with their daughters and all that. I mean one of my sisters talked a little bit more about it this time but to them, I don’t know, to them it’s just like they’re trying to put it out of their mind. Like if you don’t talk about it it’s not for real."

Lynne also talked about her family’s reaction at the time of her diagnosis and treatment.

"It’s funny because my Mum said, ‘Do you want me to come out?’ And it wasn’t I didn’t want her out here but, like, I said to her, ‘Why don’t you wait ‘til
after I finish the treatments.' I don't know, I guess I didn't want her to see me that sick, but I just felt that, you know, Maureen is here, my aunt, and I could cope with her more. Like, I knew my Mum wouldn't be able to handle it and I didn't want somebody like that around me. At the time like I didn't want somebody here pitying me.

Whereas my aunt wasn't, like, I mean she'd come over, and she'd help me but it wasn't constantly at me, 'I'll do this for you, you're an invalid now.' And then my husband was very, very good, he was excellent throughout the whole thing too. You know, really lucky that way to have.

My daughter was very, she doesn't talk about it either. Like, she won't talk about it. I mean, in fact she got really, I know my, when my mum and my sisters and everybody were phoning here and I said, 'Mum, everything's fine, don't worry about it, it's just a small lump.' Like they didn't believe me so they started phoning her and like she got really angry. I don't know, I guess it was her way of coping with it. She said, 'Look my Mum's fine. There's nothing wrong, she's just got a little lump and, you know, don't worry about it, you don't have to be phoning here all the time.' But she never, ever accepted it either.

And I mean, you know, every so often I'll bring it up to her and say, 'You know Wanda, you know, this, there's a possibility that somewhere down the line that, you know, you may get cancer.' I mean she's twenty-four. Like she still won't accept that cancer is cancer. Like, to her it's just some trivial little thing that happened, it's all over with and I'm healthy and she doesn't want to hear anything else about it.

Later Lynne talked more about her family and some of the changes she has noticed.

"Yeah I find, like, I find, like, my husband is so much more attentive, like, I mean, you know, he's changed. I mean he was always really good and that, I mean we had a great relationship, we've been married for twenty-five years, but, umm, you know, after twenty years, twenty-five years you kind of take it, you know, each other for granted and that. But I find over the last year like he's really changed, like. I mean, like, he was leaving today to go to Calgary for a week

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122 Maureen is a pseudonym.
123 Wanda is a pseudonym.
on business and, like, he phones me at work. Well, he would never have done that before, like, I mean I said goodbye to him the night before. I mean now he'll phone me at work and say, 'Okay, I'll phone you.' And he phones me every night while he's gone, and ah, but, you know little changes like that.

I guess maybe, you know, I mean it's, they get a scare eh? And they realize that, you know, some things are not forever. I mean, you know, it could be and especially after those two girls at work had died, I guess it made him realize that, you know.

Yeah, I mean it's, like, the same as my, like, my family. I mean, like, I've been gone a long time but I would go home a couple of times a year, phone my parents at Christmas and at Easter and on their birthdays and that, but my Mum very seldom ever actually called me, eh, she was, like my Mum is a farmer-type woman, she didn't believe in long distance phone calls. But now she phones me every week, eh."

I: "How's that make you feel?"

"It, it feels good, like I mean at least, you know, I mean I guess because I was separated from my family for so long that sometimes you start thinking, 'Well, you know, do they really care?' You never hear from them and that, eh. I mean, you know, when something like this happens you find out they all really do care."

During the interview Lynne also talked about her situation at work. She was working full time when she was diagnosed. She took time off while she was going through surgery and then took six months medical leave of absence while she was going through chemotherapy. At the time of the interview she had been back at work for almost a year and was really enjoying her work. She described her colleagues as "a great bunch". I asked Lynne if she talked to her colleagues about what had happened to her. She replied,

"Oh yeah, they all knew. . . I mean everybody kind of, you know, has no qualms about telling anybody their secrets or anything. It's, ah, a real close atmosphere in the department."
Okay, I found out in June, well there was a girl in our department that had had breast cancer five years previously and she died two weeks before I found out that I had it. And then a week after I found out another girl in the department also found out that she had it and she passed away in June this year. She didn’t even last a year after she had her operation. And then in October before I went back another girl was diagnosed in the department. And she, ah, she had a complete mastectomy though, she’s doing fine. Hers hadn’t spread under her lymph nodes or anything.

So, you know, with so many people in the department all of a sudden, you know, getting breast cancer like it was, everybody wanted to talk about it, everybody was really open about it. And, ah, you know, everybody was scared, everybody thought what is this and epidemic going or how, you know, I mean four people in one department in one year.

I think a lot of people were really scared and a lot of people were really, see the girl that got it a week after I got it and she was never well from the time she had her operation, she had an extremely difficult time with chemo. She couldn’t take the chemo, she was just deathly ill. She wasn’t that much older than me, she was only about five years older than me, but she was, umm, really, really skinny and, ah, she just didn’t look healthy to begin with. So and then when she got really sick well then, of course, I know for a while everybody was kind of hush, hush around me, they didn’t want to, you know, they’d go over and visit her but yet they didn’t want to say too much ‘cause they thought that well maybe I’ll get upset.

So that, I think that was a very difficult time, like everybody just didn’t know how to talk to me about it but I, I just, you know, was very open about it, and I thought, ‘You know, it’s just the luck of the draw, I mean, it could have been me and not her.’"

Lynne’s colleagues asked her lots of questions. This provided Lynne with the opportunity to talk about her breast cancer diagnosis.

"To me it was really helpful, like I, umm, like I have two cousins here in Vancouver and an aunt, and I mean, I’m really, really close. They’re just like sisters to me. I mean, I’m sure they got so sick of listening to me for the first two or three months that, yeah, but I don’t know I always found it easier to talk about it. Like, I mean, well my husband, at first he found it very difficult ‘cause he’s, he’s really, you
know, afraid of anything to do with sickness and you know he couldn’t understand why I had to talk about it. So I don’t know, to me it was therapeutic talking about it, getting it out our your system."

I: "Do you still talk about it?"

"Not that much, no. I mean it’s very, very seldom. I think once I got back to work in January, umm, after the first or second week that I’d had millions of questions asked me and then it kind of all just calmed down and just was kind of forgotten."

I asked Lynne if she had any friends other than her colleagues who she was able to talk to. She said,

"Oh yeah, yeah, I have two really good friends that, you know, I’m able to share everything with them. One of my girlfriends she had, umm, cancer of the uterus about eight or nine years ago. So she was really, really, umm, helpful and even her husband like he, he’s a very special person, like I mean we chum with them as a couple, but yet he’s phoned me at home. When I was at home and that he’d pick up the phone from work and he’d say, ‘Well, how are you feeling today.’ And like they were great, the two of them.

Even through they had different types of cancer and that I think that they really, umm, understood and they make a point of really, like there was one girlfriend who, this is another one who I’ve always been very, very close to for the last twelve years and that. And we’ve always, I’ve always seen a lot of her and we’re the type who could always share everything together and yet she was the one that, she just didn’t, she never ever came to visit me in the hospital. She came up, she came up after I got out of the hospital and that, but she’s never, I, I, like, I expected more of her than I did my other two girlfriends. And yet, ah, she just never. . . I don’t know, you can’t, I guess I can’t really say you’re disappointed in her but I felt really betrayed by her because she just didn’t give me the support that I felt I needed.

Like, I, the other two friends, like, I mean they stood by me the whole time and they supported me. Like, I mean one of the girlfriends, everytime I would go down for chemo, I mean she’d show up at the Cancer Clinic with, she gave me a different little gift everytime. She’d come with a little parcel for me and a nice card and that, yeah, I mean she went out of her way to do this. And yet I was, I mean I was, you know, we chummed with them as a couple and we were close to them but not, I was never as close to her as I was to
the other [friend who didn’t visit her]."

Lynne explained how now she reads literature on breast cancer.

"But, I mean, like every piece of material I get, I put it away, you know, I want to read everything about it and, umm. Well just things, like there’s all, almost everytime you pick up a newspaper there’s something in it about, you know, breast cancer or, umm, like there was an, an old lady in Surrey had a thing in the paper every week not specifically on breast cancer but just cancer in general. I used to read all the time, but, you know, magazines, if I see a magazine with something about breast cancer I’ll read it, or I’ve gotten pocket books at the library about people that have written their story about it . . ."

I: "Do you find that’s helpful to you?"

"Yeah, I do. Yeah, yeah, it’s, you know, I just think well, you know, she coped with it and, you know, like life goes on, you know, you just have to, I think live more day to day, umm, when you do have cancer."

Lynne also joined a support group for women who have had a diagnosis of breast cancer.

"You know, like I’ve been going through those, ah, sessions they have down at the Cancer Clinic once a month. They have a, umm, it’s a group in the evening like they have a different topic each time. And, ah, they give you lots of material and everything to read and they have doctors come in and talk to you and that."

I: "How do you find that?"

"I find it really, really good. I find it, umm, you know, when you get in a group of people that are all in the same boat as you like it’s, and everybody is so open and you get people from all walks of life, but yet you have that kind of closeness with them because they’ve all been through the same thing and it’s, I find it extremely informative. Like, there’s so many things that you, like your doctor doesn’t know but yet somebody who’s gone through it knows. Everybody tells, you know, some little story or something, I find it really, really good."

124 Surrey is a community in the lower Fraser Valley about an hour drive from Vancouver.
I: "Is it just the, sort of speakers that they have in or is it the . . . ?"

"They, ah, no actually I enjoy, like normally they have a speaker in for the first hour and then the second hour it's just everybody talking amongst each other and I find that better even than the actual speaker (laughter). You know you, you meet, I've met, you know really interesting people.

But I always thought it would be great to have something like that out here [in her community]. You know, because we are so far away from the Cancer Clinic and that, and I think that just that you need that, you know, those people. Like I mean you have all your own friends but it's not the same if they haven't gone through it. Like, you need, you know, you need to be around people and talk to people that have gone through the same thing as you. So, I, yeah, I keep hoping that they, somebody starts something like that out this way."

The second example of the incorporation of the breast cancer experience into social reality is Catherine's story. Catherine was 47 when she was diagnosed with breast cancer. She was diagnosed three years before the interview. She lives with her husband in a community in the Fraser Valley. Catherine has three children, one daughter who is married and two sons who are still living at home. Catherine does not work outside the home, but has a hobby/part-time business she runs with a friend from her home. Catherine is the woman who had recently been diagnosed with osteo-arthritis, which was causing her significant discomfort.

After Catherine had told the story of her diagnosis and treatment she talked further about how she managed the cancer.

"What I did with the cancer, when I had, umm, first got cancer and I was frightened to death, you know. And then the more you think about it, you know, it's only a six letter word and, ah, you deal with it that way. Then I didn't call it anything, and I just, just wanted to get better. And, umm, I knew I had a
choice to make, you know, either you’re going to feel sorry for yourself or get on with life and I have a good home here, nobody babied me, you know. I kept home and did exactly the same housework and nobody said, ‘Gee how are you?’ You know, or anything and I got along you know fairly well.

I have two boys and a girl and they were, I think eighteen, nineteen and twenty, and I didn’t want to upset them. And I didn’t want to upset my daughter talking about cancer so we never, and my husband couldn’t talk about it. It’s, he’s just, you know, he just freaks out so nobody talked about it. And I’d put on my make-up everyday and my hair didn’t fall out so I looked good.

And when I’d have chemotherapy they were all at work. So, umm, my husband would come home, drop me off, like he said there’s nothing he can do to help me, he knows I’m going to be sick so he just went back to work and left me in the bedroom to be sick. So (laughs), I went through three days of being sick and then, you know, just sort of, got through the treatment.

And, ah, that’s the way, you know, ‘cause I didn’t want the kids growing up with this fear of cancer or anything, you know, in case it ever happened to them. I wanted them to feel my mum had it and she beat it. Some people like to dwell on something and make it out and make it like a big thing, and, umm, I didn’t want to do it to the kids, you know. So they never, ah, really thought more of it than I was just in the hospital to have an appendix removed or something, you know, and, ah, I came through it okay. I’ve got arthritis now and nobody says, ‘Poor mum.’ (laughs) Just they let me go down the stairs a little bit slower (laughs) that’s it, we just get along with, with it that way. So that’s the way I deal with it.”

Later in the interview she compared her experience with cancer to that of others.

“So, ah, now I just, it’s just life, part of life. I think it’s taught me, I think in a way it was good in a way, it makes me appreciate life a lot more. And I mean I don’t think that I was real hard done by because of the loss of breasts, I look at Terry Fox’s 125 or any of them that lost a leg, then lost their life, I mean

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125 Terry Fox was a young man who had a diagnosis of cancer. He started a cross-country fund raising run to raise money for cancer research.
they're a lot worse off than me.

Yeah, yeah, there's been that, like when I had cancer at the first, it was, I'd feel bad at times, I had bad days. And you're in there having a shower and I'd have a real good cry and then I'd come out, 'Now smarten up.' Gee whiz I mean a lot of, I mean you start reading books of people that have died, important people and gosh, you know, they died and I'm still alive, heck I'm lucky."

In talking about her family's reaction to her cancer Catherine explained that her family was close, which she really enjoyed because the family she grew up in was not. She did not have her sister or mother around when she had her diagnosis. She talked more about her family.

"But, umm, well, I think we're doing okay or I am. And the main thing is that I think that I've got the kids so that they're not afraid of the disease of cancer, or something like that.

But, ah, no I've come through it and I hope with, and hopefully my children will never have it. But if they do I hope that they'll go soon and that, you know, and see about it, and get something done."

I: "In particular did you ever talk to your daughter about breast cancer or did she ever ask you?"

"No, she's never, but I told her, you know, that she should tell her doctor that I had it so maybe he'll watch her more carefully. Maybe, you know, 'cause she's only twenty-three, but you know, I would just want her checked by the physician. So, I said, you know, when they do, when they ask you the history now if you let them know just to make sure, I mean, nobody in my side ever had breast cancer either. I was the first one."

Much later in the interview Catherine talked about her family again.

"We all get along fine, I mean, I think this, umm, cancer made us closer, maybe."

I: "Do you think so?"

"Yeah I do, I think, I think we, you know, they seem to, they keep saying they care about me,
(laughter) you know. They seem to be, umm, I think it made my husband, ah, shows more affection towards me 'cause he was really scared I was going to die, you see. He thought I was going to, of course he may have been dreading that I was going to leave him with three kids, I don't know (laughter).

But, ah, no I think, umm, he's more concerned that we enjoy life more, you know. Like, he said, umm, next spring we're going to go on more holidays 'cause we haven't been doing that, you know. It's always been pay off the place, pay off the kid's education, you know, everything came first. And, you know, like he said it was a shocker, you could be dead, you know, we haven't done anything. So we're going to that, we're going to, you know, travel a little bit, on weekends go here and there, and holidays go somewhere instead of working around and saving money for, you know, to educate a child here or there, or whatever. It makes you, smartens you up and makes you appreciate life, what you have, 'cause who knows what tomorrow will bring."

I: "You said your husband was a little more affectionate."

"Well, before, he's, he never talks about things, you know. And umm, like he just said after I had the cancer, he did go to the hospital the day I had the cancer operation, he sat outside the door. I couldn't believe that 'cause he never, he hates hospitals (laughs). I mean he usually just drops me off, says, 'Okay, bye.' And I go in and register myself and up there I go but, ah, he did do that, and ah, he did come to see me every other night, you know. I was in there for two weeks so...

And he, umm phones home usually at noon now to say, 'Hi,' and what I'm doing, you know, never used to do that. And, umm, I guess that way, you know, thinking, we go out and I try and make everything we do like we're going grocery shopping tonight, so I said, we hate that you know (laughter), it's a horrible job, so I said, 'Let's make it a night we'll go out and, and have a quick dinner first.' You know, and then we'll go, make it kind of special."

Catherine didn't have any of her extended family around but she said it wasn't a problem because she had good friends and neighbours. However, she did tell one story of a friend who avoided her.
"But, you know, I think they're almost scared that, ah, I touched you, I could get cancer. And I mean (laughs) I've even had friends that I've known when you're, after I came out of the hospital and they saw me walking down the street they crossed over to the other side of the street. (laughs) You know, we're saying, 'Hey it's okay, you won't catch it from me.' You know, I guess they don't know what to say to you. Just say, 'Gee how you doing?' you know. But they, they don't know what to say to you, you know."

I: "Do you think it's they don't know what to say, or do you think that they are afraid of getting it?"

"I don't know, this is it. I really don't know. It seems so strange. Though I know after I got it I phoned, umm, and talked to all my girlfriends, and I said, 'For heaven's sakes go in and have a mammogram done.' You know, just to be on the safe side. And they all have because before they'd never bothered either because nobody's ever had it that they knew of in their family and that."

Catherine mentioned one friend she talked to a great deal.

"Well, my one friend, Barbara\textsuperscript{126}, she had lumps in her breasts a lot. And she's been having it for years and years, having them drained, she has, they have to go and they insert a needle. And so she understood, so we talked about it, you know.

We talked and then I would think of everything I had to have done. I kept thinking this is a new experience and I'd go into thinking, instead of being scared, I'd think this is something I can tell Barbara about, she's never had this done. So I'd go and have it done and then I'd phone her up the next day and this is what they did, you know. We would sort of, you know, show and tell sort of thing and that's how I guess we got through it.

I got through it because I couldn't talk to my husband because it upset him, you know. He said, 'That's death.' You know, that worried him. So I, that's, that's how is did it, you know. If somebody says, 'How are you?' I'd say, 'Fine.' I didn't feel like telling them how I, you know. I find it boring, 'Oh gee, I've got this ache here and you know I feel so terrible here and this medicine is making me so sick.' I mean I think those kind of people are boring to listen to, you know, so I say, 'Fine, I feel fine.' "

\textsuperscript{126} Barbara is a pseudonym.
Catherine also talked to women she had never met before about her breast cancer experience.

"Maybe it’s like my neighbour across the street, he knew of a lady a couple of streets over that had come down with, they had diagnosed her with having it, and she was really upset. So, he said, ‘Would it be okay if she phoned and talked to you?’ And I said, ‘Sure.’ And there’s a lady in Maple Ridge, there’s a woman I’ve had phone me from Surrey that I don’t even know who they are, they just phone and say, ‘Well a friend of mine had told me about you.’ And, you know, and when we talk to each other it’s not so frightening when you talk to somebody, you know, you’re all talking about it. You get talking with other people about it, and you, it kind of helps, you know, if you keep a, keep a good attitude about it, you know, that’s, that’s the thing, you keep up."

Although Catherine talked to friends, and some strangers, about her experience with breast cancer she did not join a support group.

"I suppose for people that, ah, if they want, you know, if there was something that they, I don’t know if it would have helped me or not. I mean, I don’t, some of the places you go and they sit and talk about it, I don’t, it’s depressing. I mean, I don’t want to hear, oh, you have to go through this and you’ll feel, you know, and they’re always so down. I don’t want to be down. I mean, I can be down at home easy enough. I want to feel good and hope and, you know, so I probably wouldn’t have gone to it.

I mean, they gave me a book to read on chemotherapy and all this stuff. And after I read it, oh my God, I’ll, you know, this is really terrible. I was sick and scared to go, you know. So, umm, I didn’t find it a great book to read. I just try to, I’d rather have someone sort of tell you than, you know, that has gone through it, you it sort of was, ‘cause it affects people differently and that, you know."

Catherine also had concerns about the way in which money was being spent on cancer research and on services for women with

127 Maple Ridge is a community in the lower Fraser River valley about an hour and a half drive from Vancouver.
breast cancer. She had serious edema in her arm and had to return to the Cancer Clinic to have fluid pumped from her arm. She was frustrated because there were so few pumps available at the Clinic. First she had to go on a "waiting list". Then she could only use the pump a couple of times before going back on the waiting list.

"I read an awful lot of books in the health food store and stuff and I read up on an awful lot of things and I think the Cancer Society\(^{128}\) does a wonderful job helping people. I believe they were close to cures and they didn't really want a cure. I mean this is awful to say, I don't know, but I think, umm, they could have done a lot more for us than they're doing, you know. They've had, they've found things that would have worked and then they've squashed them and you've got to go across, go to Mexico or elsewhere for them. I found it in books, I mean I, I researched it, when I got it, I researched on every book I could find in libraries and health food stores and, and things, and talked to some people, you know, that have said this.

I mean, I don't know and I mean I'm very grateful for what they did for me. And this money that's being spent I wonder, cause you know at the Cancer Agency they're not getting any money. They only have three of those, ah, pump things for your arm.

I mean that's terrible, I mean, you, I've know lots of people that they've, their husband or somebody has died and they have left money to the Cancer Society thinking it's going to help them. I didn't realize this 'til I went in there and this woman said, 'Well we left them thousands of dollars to you [Cancer Agency].' And the nurse said, 'Well we never got it unless you put on it saying where it goes.'

I mean they put so much into, into research. And, ah, those chemists and what are paid, I don't know, I really don't know what they're doing with the money. Yeah, I just wonder, you know I really, I really wonder if it's really going for a, and maybe would they have a job if they found a cure, or are they really working at it?

And, umm, research well, I don't know and how come they don't have, they sure don't put too much of it

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\(^{128}\) Refers to the Canadian Cancer Society.
towards women with breast cancer, you know. They, they haven’t been pushing that to have mammograms done or anything like that, you know."

I: "So you didn’t know about the, getting a mammogram done?"

"I had wondered, my doctor, you know, I had mentioned it once before and he said, 'Oh, you don’t do it until you’re forty or fifty.' And I thought oh, oh you know, that’s strange, and I’m hearing on T.V. that in the States they’re, I mean I know you have to pay for it and it costs like $80. Everytime you go in but we have medical here and we pay for extended medical and everything and they’re not doing it, you know."

I asked Catherine how she would like to see the money being spent.

"Well I think, ah, first thing try, try to get people in that, and get women in and have them examined so they don’t die. And men too, men are getting breast cancer now, so maybe when men get it they’ll pay attention. It seems like if it’s a woman, I mean, I feel that you go to a doctor and the man, the doctor falls all over your husband, you know. Good heavens, a little problem and it’s a big deal, but if it’s a woman, you know, it’s a woman. And, ah, I mean, I feel that we’re equal to men any day, any time."

I: "You feel that the treatment isn’t equal?"

"Yeah, well, sure, I think now that if men were getting it, maybe they’d take it a little bit more serious."

Catherine also commented on the cost of the prothesis, and that women on low incomes may not be able to get a good one. She also said that her prothesis was starting to disintegrate after only two years, which made it even more expensive.

A. Representing Self - "Mine is not as bad as some other people’s"

Cancer means not only the loss of a breast to me, it is a gaining of fear, a chance at death. It is, potentially, a loss of everything one treasures. Philosophically speaking, death is always a certainty,
whether one is ill or healthy. But whereas a healthy person does not usually think about death as a near future possibility, a person with cancer comes face to face with it. (Crowie 1994:74)

Cancer is equated with death. Most people do not think much about their own mortality. However, a woman who has had a diagnosis of breast cancer must face it head on. A personal story of a diagnosis of breast cancer includes death as a possible outcome. One aspect of disruption in personal biography is the need to deal with the possibility of death. Participants repair this disruption by representing themselves to others as normal, almost by denying the seriousness of the breast cancer diagnosis.

In this section I explore some of the themes participants use to talk about living with the uncertainty of dying. They deal with this uncertainty by representing themselves to others in the best light possible. One theme they use is that their personal experience is not as bad as it could have been, or not as bad as other people's. Another is that they were able to cope with the process of diagnosis and treatment. They describe the psychological strategies they used to help themselves and those around them deal with the horrors of the breast cancer diagnosis and treatment.


In this section I explore how the participants talk about their breast cancer experience as being not as bad as it could have been. The main way they do this is by comparing their breast cancer to the experiences of others with other health or
personal problems. These comparisons are similar to the comparisons talked about in the evaluation of treatment, and done for much the same reason. The majority of the comparisons minimize breast cancer, making the experience not that bad, and contributing to the evolving discourse of hope.

One type of comparison is to compare the participant's experience to that of someone else with another type of illness. Part of the comparison is to say there is "always someone worse off than you."

"I had a girlfriend come to visit me when I first came home from the hospital after the first operation. She walked across the room and I noticed there was something wrong with her leg, and, ah, I discovered she had Multiple Sclerosis so I felt a little luckier. I really did, I thought I'm lucky... But you know, cancer of the breast seems so mild, if you catch it in time that's the big thing." (Karen)

"I'll tell you the same thing I tell everybody, cancer may come back one day, but I pray I never get Alzheimer's. And my daughter's reaction is, 'If you get Alzheimer's mum, you won't know a thing about it.' I said, 'But the way I look at it now, I'd be an awful handful and I'd rather have the cancer to deal with.'" (Stephanie)

A second type of comparison is to talk of the breast cancer as being "not that bad", or something which "did not have much impact on my life". In these cases the participants usually compare their experience with breast cancer to other life experiences. Lisa had multiple health problems, including breast cancer. When I asked whether her health was back to normal after the diagnosis of cancer she responded,

"Oh after the cancer treatment, yeah. It's the other things, arthritis mostly is, ah, the one that's holding me back 'cause I can't walk and now the eyes are holding me back because I can't see, but outside of that I'm, I'm back to normal. As normal as I can be."
A third type of comparison is that breast cancer is not as bad as other types of cancer. Cancer in the breast, which is an organ on the "outside" of the body, is not as bad and can be successfully treated. Whereas a cancer on the "inside" of the body is worse and much harder to treat.

"But I'd say if you have that dreaded disease it's best if it's on the outside of you and not internally, you know. A breast you can get that away, but inside that's pretty dangerous when it gets inside you. And a lot of women die from this too. Yeah, but that's the ones that don't look after it in time. I'm sure it is, they've let it go and let it go." (Leslie)

"I just truly believed that everything was going to be fine, you know. It's like, ah, I just felt, ah, that if you're going to have cancer, let it be in the breast where it can be treated. . . I suppose, ah it depends I guess how bad it is, but I, I think when they tell you that it's a very early detection I think that just lifts you right up." (Leanne)

The participants construct a breast cancer which is outside the body, and therefore is treatable. This is done by shifting the boundary of the body to exclude the breast. This is a way of changing the conceptualization of the body, to exclude a body part that has become cancerous. Placing the cancer outside the body is a way of keeping the cancer outside of the defined self. This makes the cancer less serious, as the cancer has not really invaded the body itself.\(^{129}\)

Comparing their experience with breast cancer to the experiences of others is a way of minimalizing their disease, in much the same way as some of the participants did when they compared their experience with breast cancer to that of other

\(^{129}\) This is a conscious use of the military rhetoric (Sontag 1979, Patterson 1987)
women during their story of diagnosis and treatment. Talking about their breast cancer in this way uses a narrative of the cancer being "not as bad as it could have been." It reinforces the discourse of hope as learned during the process of diagnosis and treatment. Creating hope for the future, and then expressing this hope to others through the telling of their story, is a way of representing themselves as having had a diagnosis of cancer, but not dying from the disease. They represent themselves as survivors.

2. The Rhetoric of Dealing with Adversity

In their breast cancer stories the participants described how they managed or coped with having a diagnosis of breast cancer, going through treatment and living with the fear of reoccurrence. The main theme in these descriptions is how they have dealt with adversity of being diagnosed with cancer. In this section I examine some of the rhetoric used by the participants as they describe how they dealt with adversity. This provides some insight into culturally appropriate styles of dealing with cancer and dealing with adversity.

By and large the rhetoric used is very positive, very upbeat. It is as if most of the participants coped with their breast cancer very well.

\[130\] In some cases the adversity is not the diagnosis of breast cancer but rather another event or health problems, such as a spouse's illness or death. However, the rhetoric used in these cases is the same.
However, there are a few of notable exceptions. One was Stephanie, who lost her husband at the same time as she was diagnosed with cancer. She said that "I handled it my own way by going crazy."

The other was Angela, who was in her late 20's when she was diagnosed, and said she became depressed for a while after her treatment. The other participants who talked about bouts of depression or crying said that they were very short and over quickly, much like Catherine’s.

Much of the rhetoric was a description of the mental state of the participants. It is clear they felt having a good mental state made the cancer easier to cope with. The statements were framed as having a "good" or the "right" attitude, having a "strong mind", having a "positive outlook".

"... I do think that if you, if you’re happy, I do think that it keeps disease and things away." (Jean)

"I really feel a positive outlook on life has really helped bring us this far." (Jill)

"Square your shoulders and get through the best way you know how." (Stephanie)

Another aspect of having a positive outlook is "looking on the good side", remembering that even if the treatments are not pleasant they are going to help. Susan had chemotherapy and explained she was not very upset about losing her hair.

"And, no it didn’t [bother] me losing my hair and stuff, you know, I knew it was going to happen."

I: "And that was just part of it."

"Yeah, just part of, you know, you can’t look at the bad side of things you’ve got to look at the good side of things. ... Well the chemo is going to help you. I know for a lot of people it makes them quite ill. But once they get over that, umm, you can’t
always be down and depressed, you better stay up over everything and keep your spirits up."

One explicit coping strategy five participants talked about was maintaining a sense of humour, in particular when going through treatment. They explained that it helped if to be able to laugh at themselves and not take things too seriously all the time. Nancy said that making other people laugh made her feel better.

"The only thing I can say is, I can't stress enough, is the humour. You have, the people should have a sense of humour. I mean I really realize you can't develop one at this particular point, but, ah, if you do for heaven's sake, you know, just look at things and, and try to see the funny parts. . . It may not seem funny but my God, you know, as I say you can't sit around and wring your hands and moan and groan, you have to get on."

The way the rhetoric is used, it is as if the positive outlook not only helps make the participants feel better, but also could have an effect on the course of their cancer. The popular literature has developed models which include the use of the mind in helping control the growth of cancer cells (Seigel 1986). This is an important element in the construction of a discourse of hope for the individual participant.

The use of rhetoric about attitudes also reflects the importance of stoicism in facing adversity, and in particular illness or pain. It is important to be stoic and not let others know what is happening. The participants spoke about how important it was when they were going through, or had just finished, their treatment that they did not want to be treated by other people as if they were ill or disabled. Therefore many of the participants made an effort to maintain their normal life
while going through treatment.

"You really want normalcy . . . in your life. You really do 'cause that sort of makes you feel like you're not giving into your illness. . . . You've got a fighting chance against it." (Amy)

Once finished with the treatment, it is important to get back to normal as quickly as possible. For some of the participants this meant returning to work. From then on it is important to keep busy and not to dwell on the illness that has passed.

"I don't always like to keep thinking about what I've had done. . . . I don't like to bring it up. I like to keep it, I've got over it real good, I like to put it out of my mind." (Leslie)

". . . besides this isn't going to affect you that much, you carry on with your life as, and, you know, put it behind you." (Eileen)

It seems that one way for the participants to deal with breast cancer is not to act sick. It is as if once they start acting sick or looking sick, such as when they lose their hair during chemotherapy, the cancer and illness takes on a new meaning. As long as they can carry on, then the cancer is not that bad. Maintaining a normal life is a way to minimalize the impact of the disease, especially on other people around them.

It is as if the participants do not want to acknowledge to themselves or to those around them that they are sick. At the same time they are very much aware that they have cancer and that

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131 DeSantis (1979) found a similar response in the interviews she did with women who have had a diagnosis of breast cancer.

132 This is reminiscent of Parson's (1979) traditional sick role in that the patient is responsible for trying to get back to normal as soon as possible.
it is a life-threatening illness. This is a contradiction which most of the participants do not talk about.

There is no doubt that part of maintaining a positive outlook and a good attitude is to help family and friends get through the cancer. Presenting themselves to others as normally as possible minimalizes the impact of the participants' illness. This is important, so others will treat them normally and will not be afraid of cancer. This is particularly important in the case of children. Participants do not want their children to be afraid of cancer in case they get it in the future. This will be discussed in greater detail later.

The disruption caused by the diagnosis and treatment of breast cancer is managed through a series of strategies to assist the participants in "getting through". Minimalizing the disease and using the rhetoric of dealing with adversity is a way of creating hope for the future. It is a way of reinforcing the discourse on hope the participants learned during the process of diagnosis and treatment. What is interesting here is that the discourse of hope is now maintained in order to protect other people. It seems the production of a discourse of hope is an acceptable way of dealing with cancer in Canadian society.

B. Breast Cancer as a Family Experience

This section explores how the participants constructed their diagnosis of breast cancer as a family experience. Most of

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133 This is particularly important in the case of children. Participants do not want their children to be afraid of cancer in case they get it in the future. This will be discussed in greater detail later.

134 For this research family is loosely defined and used slightly differently by different participants. I am choosing to follow the participants and describe a family as they do.
the participants talk about their families during the story of their diagnosis and treatment. The families enter the story at the point participants decide who to tell they have cancer. Usually it is the family who are living with the participant at the time of diagnosis, such as spouses and children. However, some participants decide not to tell certain members of the family or time how they deliver the news of the diagnosis differently depending on the relationship.

During the interview the participants were encouraged to talk about their families and their relationships. If the participants did not volunteer much information about their families they were asked specifically to talk about how their family members reacted to their diagnosis of cancer.

The participants talk about their families in terms of the disruption their diagnosis had on the family (Bury 1982), not only disruption of the present family but also of the history of the family. They incorporate their diagnosis of breast cancer as part of the family history. It may have an effect on the future of the family as well. The diagnosis of breast cancer disrupts the whole family, not just the woman diagnosed, and the participants describe how they try to manage this disruption and the effect it has on others as well as themselves.

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135 Spouse in this case refers not only to those legally married but also individuals to whom the participants have a relationship similar to a spouse.
This section is divided into three sections, dealing with:

1. Spouses,
2. Other family members,
3. Creating a Family History of Breast Cancer.

1. "Will he leave me?" - Talking about spouses.

For those participants who are either married or living in a common-law relationship (22 out of 32 participants\textsuperscript{136}) the first person in the family they tell about their diagnosis of breast cancer is their spouse. Because of their intimate relationship the spouses are in positions to provide support. However, a diagnosis of breast cancer also has the potential to destabilize a relationship and possibly lead to a breakdown of the marriage.

In the narratives there is an underlying discourse that not all spouses are supportive in cases of a diagnosis of breast cancer. Jennifer, who was not married or in a steady relationship, said,

"One thing that I was grateful for, and this is an awful thing to say, was that I was not in a relationship. From what I've heard other patients say is that they've, some did not get any support from their spouse. And I was glad I didn't have to deal with that."

Karen, who was married, said,

"You know, there's nothing, I would tell other patients, there's nothing to be ashamed of. You know, unfortunately I've known women who've had it done and their husbands immediately walk out the door. So they go into that with that fear and, ah, it's, it's not important when it's your life."

\textsuperscript{136} There were nine participants who were either widowed or had never been married. There was one participant who was temporarily separated from her husband at the time of her diagnosis.
I: "Well you wonder how strong the marriage was before?"

"Well, I don't know, it, ah, I don't understand, I just don't understand when people, but I've seen quite a few women that's happened to."

There seems to be a common understanding that many men leave their wives after a diagnosis of breast cancer. Whether this is a result of the cancer and the threat of death, or the loss of the breast and loss of sexual attractiveness is not specified. However, the participants seem to make the assumption that their spouses may not be supportive and seem relieved and grateful when they are.

The majority of the participants' spouses were supportive, but three participants indicated their spouses were not. In two cases the spouses were very ill, one had lung cancer and the other had a head injury. The third participant was Andrea, who said her whole family, including her spouse, "denied the cancer". She tried to talk to them about her cancer, but they did not want to discuss it. She found this attitude extremely frustrating.

However, most of the married participants indicated their spouse was supportive, the most common statement being "my husband was very supportive." This sentiment was often reiterated a number of times during the interview.

The participants indicated the support from their spouses

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137 In the interviews, approximately 40, I have done with women who have had a diagnosis of breast cancer I have only talked to one woman whose marriage broke down as a result of her diagnosis of cancer. She explained that the marriage was not going well and the diagnosis of cancer was the final blow to the relationship. She was much happier to be out of the relationship.
was extremely important in their decision-making about, and going through, diagnosis and treatment. For example, Virginia told how her common-law spouse went to all her doctor’s appointments with her.

"Yeah, you know it was a traumatic thing, but he was the best one there, he really saved my life, he came through. He was there all the time. And whenever I went to the doctor’s, he came too. And ah, ‘cause a lot of times I don’t listen to all what I hear half the time. So he would listen to it all and then ask me questions. Sometimes you don’t pick it all up at the same time, you know."

Other participants talked about how difficult it was for their spouses to deal with the diagnosis of cancer. The spouses were afraid the participants might die. But despite their fears and concerns they spouses were supportive.

When asked, Nancy talked about her husband’s reaction to her diagnosis,

"Umm, he was worried. But like I say, when, when it came time to have the operation it was, you know, get rid of it, whatever you have to do, cut her head off if you have to (laughs). Get rid of it. You know and that’s the way he is anyway, ‘As long as she’s okay I don’t care.’ And that’s his attitude. It wouldn’t matter to him if I went in and had my boobs cut off, my rear end cut off or whatever as long as I was okay, you know. So like I say, he was worried naturally, I could tell, he said it was okay and, but then when I had to go in and have the second one of course he was worried again and figuring that maybe they hadn’t got it all, you know. But, ah, he’s very, nothing really fazes him that much, you know, not outwardly, but he does worry."

Leslie also talked about her husband’s reaction to her diagnosis.

"I felt, well, I can’t let anything get me down, no way. I know it got my husband down a bit and I says, ‘Don’t think about it, just never mind.’ We keep active around here, we’ve got lots to do on this place."

I: "So it did bother him a little bit in the
beginning?"

"Oh yeah, he was definitely a bit, yeah, with the first one. The second one that was a breeze. I knew what was coming and everything so let’s go, let’s have it done and finished. . . I got over it so well so that’s why it kind of lifted him up too, you know. It was, ah, he took me into Vancouver everyday and ah, I had my treatments in there and there was nothing to that really."

The participants are very grateful for the support from their spouses. Even Amanda, who had just separated from her husband, said he was supportive of her as she was going through her diagnosis and treatment.

During the interview many make the point that their relationship with their spouse, even their sexual relationship, did not change after their diagnosis and treatment. This was expressed as if they expected the relationship would change as a result of the breast cancer.

A few participants indicate that their relationships improve, their spouses became more affectionate after their diagnosis and treatment, in much the same way that Lynne and Catherine talked about the changes in their relationships with their husbands.

The participants in steady relationships realize the potential for the diagnosis and treatment of breast cancer to disrupt the relationship. This recognition is the basis of the horror stories of spouses who have left women who have had a diagnosis of breast cancer. In most cases the participants talk about how their relationship was not disrupted and their spouses were supportive.

The support provided by spouses is based on a shared
understanding of breast cancer and the impact it has on the life of the participant. Those spouses, such as those ill or who denied the breast cancer, who did not share any common understanding of the breast cancer with the participant were unable to be supportive. The reactions of the participants' spouses is a potential threat to their evolving discourse of hope and reconstruction of self and identity.

2. Other Family Members

The participants' diagnosis of breast cancer has the effect of disrupting the normal relations in their families. These disruptions are some of the most troubling for the participants. They are constantly struggling to mend or overcome these disruptions.

The participants' descriptions of the impact on their families of their cancer diagnosis occur at the time they are making a decision about who to tell and when. As with their spouses, many participants at first describe their family as being supportive.

However, as they continue to talk about their families they describe reactions to the diagnosis which include shock and fear. As they talk further about the day to day response to the cancer, both during and after the treatment, there is a wide variety of responses, some of which are very disturbing to the participant.

For ease of discussion I deal separately with different categories of family members. First I discuss relationships with parents, then relationships with children, and last
relationships with members of the extended family.

A number of the younger participants had parents still living at the time of their diagnosis. These participants described their parents as being "very upset". Angela described how her mother wanted to take control of the situation, which Angela found frustrating.

Having a daughter diagnosed with breast cancer would be distressing for any parent. Most parents understand they will die before their children. Having a child diagnosed with cancer challenges that understanding. The diagnosis of cancer, and the possibility of death disrupts the structure of the family.

There were two participants who talked about not wanting to have elderly mothers around during their treatment. Denise explained that around the time of her diagnosis she had seven children, some foster children, at home and could not cope with her elderly mother as well. It was difficult for her to tell her mother that she did not want her around.

In a similar story, Anne described how she did not want her mother around when she was going through her treatment and got her friend to ask her mother to leave. She found it more stressful having her mother there than not, because she understood her mother was afraid for her. Anne described her mother as feeling guilty because Anne had breast cancer and she did not.

There were also participants who described their parents as being supportive and providing assistance. As previously mentioned, Lynne explained that she now has more contact with her
mother in eastern Canada than before her diagnosis.

Twenty-five of the participants had children. Their ages ranged from six or seven to young adults.

The most common description of children's first reactions to their mother's diagnosis of breast cancer is "fear". For many children this is the first time they realize their mother is getting older and will not live forever.

"It's amazing, isn't it actually, how your family, umm, sees you in a different light after when something, you know, before mum's always around and mum's there but something happens and I think they... I think in my case because I've always fortunately been in good health, and perhaps they just never expected me to be sick."

I: "Do you think it changed their attitude to you?"

"No, not really but I think they realize that they're not getting younger either, (laughs) you know what I mean. They're not getting younger, they, they're becoming more aware that they have to start looking after their bodies." (Karen)

The participants express concern about the level of their children's fear, such as Catherine not wanting her children to be afraid of cancer. Denise talked about her children as well,

"For my kids that was lookit guys, I teach you that cancer can be beaten. You know, it doesn't matter what part they take off you, you still can get on with it and, you know, that was really important to me."

I: "Why was it so important to teach your kids that, to get on with it, that cancer can be beaten?"

"Because they're, you know the TV programs that are out that kids see usually they die. Usually they die, they don't make it, like it's a nice, beautiful movie but they end they're gone and I sure wish that they would make some movies where they've beaten it.

Because I think there's a lot of, I don't know, not, it's not taught properly that cancer can be beaten in a lot of areas, not just breast cancer with, you know, education and that sort of thing and people not being afraid, you know."
Like when I got this lump well I'm afraid to go to the doctor, I'm afraid he's going to say it's cancer rather than, it would be nice to see programs where people actually have, you know, reacted like I'm not sitting here blowing my horns but I went to my G.P., I took the bull by the horns, I didn't sit back and wait, I didn't let it metastasize to my nodes and that sort of thing."

The message the participants want to pass on to their children is that cancer is survivable, there is hope for the future.

Those participants with very young children sometimes have a difficult time talking to their children without scaring them. As Rebecca said, when she talked to her young son sometimes he would respond and other times he would not.

Many participants who have adult children indicate that their children were concerned and supportive during the period of diagnosis and treatment. However, a number of participants express frustration with their children's response, especially that of adult children. They feel that their children are denying the diagnosis of breast cancer.

In part the participants' frustration stems from an inability to talk to their family about their experience when they need to talk, and in part from a concern that if their children, particularly their daughters, deny that they are at increased risk of breast cancer they will not be diligent in their monitoring of their own health. I discuss this frustration further in the next section.

The participants' descriptions of the reactions of members of their extended families are very similar to those of parents and children. The primary reaction is fear. The participants
react the same way in trying to counter some of those fears and to pass on information about the disease.

There is also the same frustration when members of the extended family deny the breast cancer diagnosis. However, there are also participants who have the most support and assistance from members of their extended family, in particular cousins and sisters. Much of the support is not only emotional but the very practical support of driving the participant to appointments and helping with household chores while they are ill.

There is one major difference between the participants' dealings with parents and children and with their extended families. There are cases were participants choose not to tell certain members of their extended family about their diagnosis of breast cancer. Laura and her husband chose not to tell her husband's side of the family and she explained why,

"Umm, it’s a personal thing I think and, umm, he didn’t want them to know so I just went along with it. It was, it’s kind of, umm, traumatic in a way for him because his mother had breast cancer and died of it. And this is one reason, umm, let’s say he did that, he just no, he didn’t want them to know so I went along, I didn’t care one way or the other. If I’d wanted them to know I would have let them know on my own, but, ah I thought my sister should know because she has a daughter and, and ah, it could be in the family."

In talking about other family members the participants tell the story of how their diagnosis disrupts the lives of others. Some of these stories include short stories of how some people in the family are able to successfully cope with the diagnosis and provide support for the participant.

Those who are able to provide support are again those who share an understanding of breast cancer with the participant and
therefore are able to be supportive. The shared understanding is that breast cancer is not necessarily a death sentence but can be survived.

This shared understanding allows these family members to also share in the participant's evolving discourse of hope and to overcome their own fear. This allows them to manage the disruption caused by the breast cancer in a similar style. These people support and reinforce the participant's construction of breast cancer, giving this understanding further validity.

On the other hand there are the family members who do not cope well and are a source of concern for the participants. These family members do not share the participants' construction of breast cancer. Some deny the cancer or do not talk about it. This prevents the participant from successfully managing the disruption.

As a result participants become concerned about the impact their diagnosis may have on the future experiences of others. This is a major challenge to the discourse of hope and the personal construction of breast cancer as survivable. It takes further biographical work to incorporate these challenges into the breast cancer story. It creates an account that is not coherent or smooth.

3. Creating a Family History of Breast Cancer

As discussed previously, in the participants' construction of models of breast cancer one of the risk factors commonly identified was having a family history of breast cancer or
All the short interviews were done prior to the discovery of the first breast cancer gene BCRA 1 (Canadian Breast Cancer Research Initiative 1994), although there was discussion in the media about the search for the gene. It is interesting that many of the participants did talk about possibility of a genetic, or familial, risk of breast cancer.

In describing their models of breast cancer many of the participants mention whether or not someone had breast cancer or cancer in the past. Now that they have had a diagnosis of breast cancer the discourse changes to talking about their concerns about the future and whether or not their daughters, or in some cases granddaughters, are at elevated risk of getting breast cancer. Some of this discourse is tinged not only with fear, but also with guilt that they may have brought breast cancer into the family.

"Yeah it makes me think maybe it's inherited through different families, like breast cancer is inherited through families, like my boss's, umm, wife, umm, all the women in her family have breast cancer, a lot of them, all the women in her family have breast cancer, all the sisters, umm, the mum, the aunts and she said when she found her lump which was sort of in the middle of the breast she was not surprised one bit and, ah, I think a lot of it is inherited."

I: "Does that make you concerned about your daughter?"

"Yeah, well, it makes me very concerned for my daughter but maybe it will miss my daughter and get my granddaughter. That has been really frightening that maybe I could pass it on even to my granddaughter so that, that worries me quite a lot and I make my daughter go for a mammogram. Well, she's, umm, twenty-eight so, yeah, I make her go." (Robin)

"Then I've got a granddaughter too, so, and that's down, for the granddaughter, that would be on both sides of the family, it would be me and her other
grandmother. So, it’s, it’s a bad thing. I don’t know why women have to get this anyway (laughs), you know, why is there such a thing like that I’ll never know. It’s not fair. I’ll just hope for the best that she can be without this. It’s not always inherited either is it... Cause when I was down in the States once I talked to a woman and she had, I don’t know whether it was breast or not, but she had cancer too. And she said she researched down both sides of the family and away back and nobody ever had it, but she got it. So it’s not always in the family." (Leslie)

Some of the participants try to educate their daughters about breast cancer and how best to protect themselves. They encourage their daughters to tell their doctors their mother had breast cancer, have regular checkups, do breast self examination and have annual mammograms138.

Participants are also concerned about trying to get their daughters to lower their risk of breast cancer by adopting a healthy lifestyle. Sarah was relieved when her daughter had a child. Sarah felt that now her daughter’s risk of breast cancer was lower. Mary’s approach was slightly different. She had become active in a breast cancer organization and was trying to raise awareness about breast cancer and raise money for breast cancer research.

In creating a family history of breast cancer the participants are constructing a future that does not have much hope. This is contradictory to much of the work the participants do in their account of constructing a future that is hopeful. Mary, with her activist stance, is trying to maintain hope through her work in raising awareness and money. This challenge

138 Whether annual mammograms should be used for women under the age of 50 who are at elevated risk is still being debated (Olivotto et al, 1995).
to the discourse of hope produces an opening for uncertainty and
doubt to re-enter the illness story. The possibility that cancer
will cause death creeps back into the illness narratives and
challenges the biographical work the participants have done to
this point.

C. Breast Cancer and Social Interaction

In this section the disruption in the personal biography
caused by the diagnosis and treatment of breast cancer goes well
beyond the bounds of the family. There are limits to the ability
of the individual participant to manage the disruption.
Interactions with people who share the participant’s
understanding of cancer are easily managed. However,
interactions with people who do not share the participant’s
understanding introduce another element of uncertainty into the
relationship. In cases where the relationship is one of
friendship or employment the consequences of the uncertainty can
be devastating, both emotionally and financially, for the
participant. If a participant did not talk about friends,
neighbours or co-workers then they were asked to talk about the
reaction of friends and others to their diagnosis of breast
cancer.

I now explore how the participants tell the story of their
breast cancer experience to include friends, neighbours and
coworkers. The participants include these people in the story at
various points. Some participants describe early in the story of
diagnosis and treatment how friends and neighbours assisted them
during the treatment period, much the way that Anne talked about the role her "secretary" took in caring for her during treatment. For others disclosure to friends comes later, only after the period of diagnosis and treatment has been completed.

The degree to which the participants include friends and others in their stories varies greatly. Some simply mention talking to friends. They did not want to "dwell" on the cancer but rather wanted to get back to normal relationships and activities. For others, like Anne, friends played a critical role in her story.

There were three participants who chose not to tell their friends about their diagnosis of breast cancer. It is interesting to note that all three were looking after spouses who were very sick. What is important in their story was how they got back to their everyday activities as quickly as possible. They would talk about their experience if it "comes up in conversation" but they did not want to "dwell" on their cancer, or were unable to dwell on their cancer, because they had to care for a sick spouse.

"But I suppose because I don't say anything about it, nobody else does."

I: "Does anybody know you have breast cancer?"

"Some of my friends do. Yeah, but I suppose that's gone in the back of their minds like it has mine. You know if I kept it in the foreground they would maybe ask me something, maybe when they say to me, 'How are you feeling?' Maybe that's what they mean, but I say, 'Oh fine.' You know, and without even thinking even when I'm, even when I'm not fine I'll say that, it comes out. (laughs)" (Heather)
In all three of these cases not telling friends or other people fits into the participants' construction of the breast cancer experience. They see the cancer experience as over and done with, something that was just a part of their life, although two also talk about the cancer as the probable end point of their lives. With the construction of the cancer being over and done with and the day to day reality of having to care for a sick spouse, the cancer is a relatively minor event in their lives for which they do not require support from friends.

A number of participants talk about the friends who were "supportive" while they were going through treatment. Support ranges from just being in touch regularly and concerned to assisting with driving to treatments and providing direct care.

"I went to my girlfriend’s and stayed there a couple of days so he [the doctor] knew that I wasn’t at home chasing kids."

I: "Why did you go to your girlfriend’s?"

"Because she lives on her own and she, she’s got a spare bedroom and that way there was somebody with me all day because I was still kind of wobbly and my arm was sore . . . And my husband was, umm, on afternoon shift when he doesn’t get home till one thirty so she figured it would be better if I stayed down there at least she was there all the time if anything, you know, did happen. And well my husband came down for lunch and all that kind of stuff, you know, and he went to work from there, but I only stayed two days anyway." (Nancy)

Denise, the participant with seven children, had a very unusual and heart-warming story about support she received. Denise got out of hospital right before Christmas.

"Then St. Francis Hospital\textsuperscript{139}, which was my second job, they all got together when I was in hospital and

\textsuperscript{139} St. Francis Hospital is a pseudonym.
they made an arrangement where someone knocked on my door with a, a carload of stuff. And they came in with everything from shortbread to fruitcake to Chinese food to sweet and sour meatballs, you name it. My Christmas baking and different food preparations were totally done. . . People that I didn’t even really know.

Now one of the girls that I worked with who I would say is a friend at work, but definitely not a friend outside work. Umm, through another friend she passed on a letter to me and it was fairly thick and I was expecting oh Ruth has really written me this great big cheery note. And I opened it up and I was devastated cause there was $700 in cash. She is a very church going lady and went to her minister and said there’s this single mum that’s just been diagnosed and she has seven kids and blah, blah, blah. And I guess they passed the hat."

Again, these stories of support reinforce the participants’ construction of their breast cancer. In some cases their friends help participants get through the treatment process back to normal, which is what the participants want. The friends assist the participants to get over the cancer, which fulfils their construction of cancer and contributes to the development of their discourse of hope.

This is in sharp contrast to another group of stories. There are a number of participants who tell stories similar to Catherine’s and Lynne’s, of friends who avoided them or were unable to provide the support the participant expected.

"Yeah, I lost quite a few girlfriends, I lost three girlfriends when they found out I had cancer, yeah."

I: "They just disappeared on you?"

"Well they would say rude things, 'Oh I see you still have your hair, you haven’t lost your hair yet.' And then she’d, they’d say, 'Well are they finished hacking you up.' And just different, umm, then one completely stopped phoning me, I guess she thought she

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140 Ruth is a pseudonym.
could catch it from me or something. I don't know what her problem was but I lost three girlfriends." (Robin)

Perhaps these friends did not know what to do, what to say, and were afraid of what the cancer represented.

Many of the participants, such as Lynne and Catherine, had friends who avoided them. It is almost as if the friends feared contagion from the cancer. In our society there is an understanding of cancer as a death sentence and possibly these friends were afraid of having to face the death of the participant.

The participants interpret these avoidances as a withdrawal of needed support. My interpretation is that the friends' construction of cancer envisions no hope for the future and possible death; it diverges from the participant's view. With these diverging understandings of cancer the friends are unable to provide the appropriate and expected support to the participants, and when the expectations of the participants are not met the friendships eventually dissolve.

There are also cases where participants describe how their friends were unable to provide appropriate support because they did not understand what the participant was going through.

"Yeah, I found that some people were, umm, didn't really understand, you know, didn't seem, they had sort of a tough approach, or something."

I: "Can you explain what you mean?"

"For example, I was going through radiation and I'd sort of burnt my oesophagus or something, I couldn't eat and I was, and I was lying on the couch at home and you know [feeling] kind of lousy. And, ah, this girl came over and said, umm, to me 'Oh is that all you do is lay on the couch all day long.' And (laughs) I said, 'Well I burned my oesophagus.' And oh yeah, yeah, she just kind of didn't really, had kind
attitude like get your ass off that couch and do something. And so I felt kind of, I don’t know really, I thought that was kind of a tough approach to it . . . I don’t, I guess she didn’t understand what was happening." (Angela)

Again, this is due to lack of shared understanding. In this case it occurs when people have no previous experience with cancer and therefore do not understand the difficulties the participants go through in the treatment for breast cancer. Their response lacks empathy.

In Chapter VII I identified four different cultural schemata participants use in the construction of their narratives. There are a number of different cultural schemata people can draw on to construct an understanding of cancer, even if they do not have cancer, and expectations of appropriate responses. However, during social interactions if people do not share at least parts of the same schema then expectations can not be fulfilled.

For those participants who were working outside their homes, co-workers provide another source of social interaction. Most of the participants tell their co-workers and employers they had a diagnosis of breast cancer, and most also have support from these sources. Jennifer described her work situation.

"Well my colleagues were very, very supportive, very supportive, because I used to drop in often for coffee, or before I had chemo one of them would pick me up, and I would go and have coffee. And I often stopped in and saw my supervisor, and I also was checking up on the person who relieved me because he was not trained. I only had, oh gosh, not even a half a day to train him so I came in often to see and how, what he was doing, and telling him what is happening and what to do next."

I: "Was that, was that a worry for you, or did it help you?"
"It helped me. It helped me because, ah, it kept me in contact with the staff and so when I came back to work they were quite glad to see me back at work, so they were prepared, they knew what was going on and they were informed."

As discussed earlier, returning to work is described by participants as a returning to normal everyday life and one indicator that the cancer experience, at least the treatment, is complete. Lynne was one who found returning to work was an indicator of returning to normal. Even with a number of co-workers also being diagnosed with breast cancer there was nothing much different about the work site. At the work site cancer takes a back seat to the work. Interaction with co-workers is based on their work, not on the cancer.

However, interactions with co-workers and employers are not always supportive. Julie worked as a secretary for a large downtown accounting firm when she was going through her diagnosis and treatment. She told the following story about the woman she worked for at the time.

"I used to go to my chemo and then I'd go back to work, you know, and I would work overtime and work through lunch to make up the time that I had to go from Burrard Street to the Cancer Agency right, so I made up all that time. The same with the radiation because that was like nineteen days in a row kind of thing.

And when it was all over with she [her boss] says, 'I can't work with you.' And I said, and I'm one of their top secretaries right, number one. And, ah, I kind of went, 'Oh, why?' She says, 'Well I don't really want to come around the corner and see you throwing up in a garbage can or looking sick or maybe dead with your head on the table, or I just don't want to get anything from you.' And I almost died. Yeah, so I said, 'Fine, your loss.' And I walked out on her. And even afterwards I ended up working for her mentor."
Amy was concerned about job discrimination so she chose not to tell her employer about her breast cancer diagnosis.

Both Julie and Amy were young, in their 30’s, and in the process of developing their careers, and so may not be secure in their jobs (Waxler-Morrison et al n.d., Oktay and Walter 1991).

However, as I have described, there are many different reactions of friends and co-workers to a person being diagnosed with breast cancer. These different reactions are based in part on differences in the understanding and perceptions of cancer which come from different cultural schemata.

In the work setting the potential for misunderstandings can have devastating consequences. As long as part of these schema is the perception of cancer as a death sentence there will be a fear of cancer, and along with it the possibility of discrimination against persons who have had a diagnosis of cancer.

D. Becoming a Member of the Cancer Community

During the treatment process the participants come to realize they are not the only ones going through this process. There are other women who have gone through, or are going through, a similar experience. Though the participant’s experience is intensely personal, there are aspects that are shared with these other women. When the participants realize they are not alone they become members of a group of women who have had a diagnosis of breast cancer - the cancer community.
The participants want to know they are not alone, that others have gone through a similar experience. There are specific points in the process of treatment where the participants connect with other women who have gone through similar experiences. One is during radiation and chemotherapy, where participants meet other women who had had a diagnosis of breast cancer and were having similar treatments\textsuperscript{141}. Sometimes they talk and "compare notes" about the treatment process and their experiences. Robin met two different women while going through treatment,

"Everytime you go for treatment basically there was the same women there, sitting there getting their chemo and you know, you'd talk back and forth... Yes and we'd get together and you know go to tea at one another's homes and that, it was nice and we'd be able to talk about it... It seems to help them, it, sometimes it helps me, umm, I don't like to talk about it all the time, like I don't mind talking about it for five or ten minutes but I don't want to all afternoon."

Another point at which the participants connect with other women with similar experiences is when they are making decisions about various aspects of their treatment and they seek out sources of information, beyond what the doctors give them, to assist them in making their decision. One such source of information is other women.

"But you know what I think it was my youngest niece that she said, she had cancer for nine years, she was, she was healthy. And she said, 'Oh it's nothing, they're not taking out any organs so it shouldn't bother you.' So you see that's what that is. So I says, 'Okay, it's not going to bother me.' You know, otherwise if she hadn't said that I'd have thought, 'Oh, invalid.' You know what I mean and I would have

\textsuperscript{141} At the British Columbia Cancer Agency women who have had a diagnosis of breast cancer are brought in for chemotherapy or radiation at similar times (Olivotto personal communication).
laid in bed and the whole thing. But it's amazing what little thing, umm, you know make you, well just take it seriously or not." (Jean)

Another source of information is materials written on breast cancer. The participants read from a wide variety of sources. They read medical research studies, reference materials, self-help books, biographical material and short articles from newspapers and magazines. These sources of information are very important. They provide the participants with a different perspective and make them feel they have some control over the situation.

The participants get access to this information from a variety of sources. They use their local public libraries, the library at the British Columbia Cancer Clinic, book stores, health food stores, local newspapers, and magazines from a variety of sources.

"Well what I did, what I did, so when I knew that I had cancer I tried to read as much as I could about everything. To me it was important to know what could I have. And one day I read, ah, I, the life of a doctor that had the cancer and I just couldn't believe it. Every single thing that he had, the feeling and everything, every single thing that he passed through, this is what I passed through. So I, I, that is the moment that you think you are not alone. So I read and then I, I learned by his experiences and, ah, and I continued reading but came to a point that, you can be sick of reading about cancer any more, so then I changed and then I had to read something happy, something different, nothing about cancer any more." (Allison)

A third source of information is support groups. At the time of this research the Department of Family and Patient

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142 The British Columbia Cancer Agency has an extensive library that is available to patients as well as physicians and researchers.
Services at the British Columbia Cancer Agency was running two ongoing support groups\textsuperscript{143}. One group meets once a week for four weeks and targets women going through treatment, although is open to anyone who wants to come. Anne attended this group.

The second group is an evening group that meets once a month and targets women who have completed treatment. Both Lynne and Rebecca have attended this group.

There are also a number of support and self-help groups for women who have had a diagnosis of breast cancer throughout communities in the Lower Mainland. Rebecca attended an informal support group that met in women's homes. Other participants mentioned knowing about these groups or having actually attended them, but none went on a regular basis.

These sources of information, and interactions with other women going through breast cancer, contribute to the participants' construction of breast cancer. For example, reading of popular literature elaborates and reinforces some of the concepts the women are using. One type of literature read was biographies of women who had dealt with cancer (for example Rollin 1976, McPhee 1994). Much of this material is written by or about women who are public figures and have successfully dealt with cancer.

These stories and other materials, such as the videos hosted by Ann Jillian (1986) and Jill Eikenberry (Landsbury Company 1988), present a picture of breast cancer as a cancer that can be

\textsuperscript{143} There have been a number of informal support groups run with the assistance of the social workers at the British Columbia Cancer Agency, such as the one attended by Anne.
survived and in this way contribute to the development of the discourse of hope for the future.

Many of these interactions with other women who have had a diagnosis of breast cancer provide more than just information, they also provide support and a sense of shared experience.

Support groups are of specific interest. At the British Columbia Cancer Agency there is an interest in social support (Hislop et al 1987, Waxler-Morrison et al 1991) and its potential impact on survival. Bloom and Speigel's (1984) research on support groups found that women with advanced mastitic disease who attended support groups lived longer than those who did not. Providing support groups seems to be one way to improving the quality of life, if not the survival, of women who have had a diagnosis of breast cancer. In this research the participants were asked whether or not they had attended a support group. What is interesting is the reasons why participants chose to attend or not.

Most who did attend a support group enjoyed them and found the experience useful, as described by Lynne, Rebecca, and Anne.

"However, the women who, umm, who I met in this room, they were an extraordinary group of people and we do get together quite often. I always feel very free to come back here. Which I think is very important. Helen [the social worker] creates the atmosphere that you don’t feel that you’re, that it’s silly for you to come back a year later or two years later. I guess the fact is that you can go out of remission at any time. So you, you know, it’s a good thing to have, as a matter of fact one of my

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144 Interview took place in the same room as the breast cancer support groups usually met at the Vancouver Clinic of the British Columbia Cancer Agency.

145 Helen is a pseudonym.
recommendations to the Sub-Committee was that every centre across Canada should have, must have, on site, on treatment site counselling facilities available." (Mary)

There were a variety of reasons why others did not attend.

"At different times they [the Cancer Agency] had things for meetings, you know, they had little meetings some, whatnot in there. And I was going to go a couple of times but I guess just the thought of going back into Vancouver at night time. You know, ah, I mean I never did go to one.

I went to a couple out here, they have, had at the library in Surrey it was all women that had, ah, breast cancer. . . It was very good but I found there was some ladies there that they were just there out of curiosity to see what other ladies would say, they've never ever had breast cancer." (Leanne)

"I didn't really feel that I needed a support group, like I have really a good bunch of close friends that if you wanted to talk to them or whatever they were there for you. My G.P. is also extremely good. So I didn't feel that I needed, and I know, I guess support groups you hear them whine and complain and carry on. No, no like smarten up, it's gone, accept it, get on with your life, you're, I couldn't handle something like that but that's me." (Denise)

"No I didn't have, didn't go to any of them [support groups]."

I: "You weren't interested or . . ."

"Well in a way I was but then I thought I don't know, I don't always like to keep thinking about what I've had done, you know. I don't like to bring it up, I like to keep it, I've got over it real good, I like to put it out of my mind, you know, I don't want to keep thinking about it 'cause I don't thing that's any good. I'd rather just clear it from my mind. Because in a way I would like to have gone in there but you keep on reminding yourself so much of this, you know, and I try to keep forgetting about it myself (laughs)." (Leslie)
There are practical reasons why women are not able to attend, such as living a long way from where the group is being run. The geography of the Lower Mainland area makes this difficult to overcome.

However the other reasons for not wanting to go are very interesting. There are a number of participants who did not want to talk about their breast cancer experience. For them it was more important to put their experience behind them and get on with living their lives. This concept fits with their construction of their cancer as something that is a part of their life and is now over with.

For a support group to work the members of the group must have enough in common to be able to communicate and share their experiences. As Angela indicated, the experiences of women of different ages are very different (Waxler-Morrison et al. n.d., Oktay and Walter 1991) and in her case she did not find she was able to share with women who were 20 or 30 years older than herself; their experiences were just too different. As there are so few women in their 20’s diagnosed with breast cancer, it would be very difficult to find other women to share her experiences. Amanda as well found it difficult to talk to other women because no one else had young children at home.

For a support group to be a success for the participants it is also necessary that the group members share a common construction of breast cancer. As discussed earlier, there are differing cultural schemata on which the participants base their constructions of cancer. If majority of the women in a support
group share a construction which differs from an individual participant's they will have difficulty understanding each other.

Some of the schemata participants use to construct the breast cancer do not promote the sharing of experiences. For those using the schema "Cancer as a Part of Life" or "Cancer as an Acute Illness" there is no reason to talk about their experiences. The idea of a support groups does not fit the construction of their cancer, which is over and done with. They want to get on with their lives and not talk about their cancer experience. They tend not to participate in support groups.

There are probably more participants who take part in the informal support system of women talking to women about their experiences with breast cancer than in formal support groups. After they had completed their treatment many of the participants did talk to friends, and at times strangers, about their experience, much like Catherine.

"Yeah, I got mad and said, 'This is how it's going to be and this isn't going to get me.' Some days when I was really sick, umm, I got angrier (laughs) but you know that was just my way of dealing with it and I didn't feel that I needed a lot of help. In fact, I've done quite a bit of counselling to people that I have, have gone through this, just on a one to one basis. I've got a couple of people at work, two fellows their wives have had, have got breast cancer. One's passed away, the other is a survivor too. They live in Brackendale and her family was really devastated when she was diagnosed. And I met with her and her mum and her sister, and like I just said, 'You know, here I am.' I was still going through treatment at the time but I said, 'Here I am, I'm still able to work part-time and, you know, it isn't the end of the world.'"

I: "And did that make you feel better."

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147 Brackendale is a small community near Vancouver.
"Initially, yes, it did, umm, and I think it really make them feel a lot better. I think it gave them, umm, confidence that this wasn’t, you know, there was hope for them." (Sarah)

In a sense the participants become experts on breast cancer because they have been through the experience. It is interesting that many of the participants indicate they not only enjoyed talking to other women but also found it helpful to talk about their experience. This type of informal interaction fills the same role as a formal support group. The main difference is the informality and lack of any institutional involvement.

The participants choose their level of involvement in the cancer community. Involvement in this community is another way of managing the disruption in their lives caused by the diagnosis and treatment. Involvement in the community provides the participants with further information, both documentary and personal, to assist them in making decisions and developing their own illness narrative. The level and type of involvement is dependent on both ability (those women who were caring for sick spouses or sick themselves tended not to be involved) and the schema of construction of the cancer. Those participants who construct their cancer as over and done with do not involve themselves in the community much past the completion of treatment.

It is interesting that more participants are involved in the informal support network than the formal support groups. One reason is that there is less travel involved, as much of the informal support takes place within their own community or on the phone. Involvement in formal support groups seems to involve
much more commitment. It is also necessary that those in the support group share a basic understanding of cancer in order to be able to communicate.

The formal support groups seem to work best for middle aged women who use the schema of "Breast Cancer as a Point of Change" to construct their cancer stories. If formal support groups are going to be offered as a part of the treatment for breast cancer it will be necessary for them to accommodate a wider variety of constructions of breast cancer to benefit more women.

E. Looking to the Future

Towards the end of the interviews some of the participants expand their perspective beyond their personal experience to include a discussion about more general issues. Much of this discussion is focused on the future and what they feel should be done, or what they are concerned is not being done, to deal with breast cancer. This is the politicization of the breast cancer experience.

At the time the interviews were being conducted there was an increasing interest in the topic of breast cancer. A number of special interest groups developed in the United States (Soffa 1994) followed shortly by an increased interest in Canada (Batt 1994). Many of these interest groups developed out of local support groups.

These groups were concerned about a number of issues, including lack of appropriate resources and information for women with breast cancer and their families, lack of progress in breast
cancer research, lack of consensus on the treatment protocols and mammography, and the lack of voice in decision-making for women with breast cancer. For example, dissention about the interpretation of the results of the National Breast Screening Study (Miller et al 1992a, 1992b), a clinical trial on the effectiveness of mammography, was starting to come to light. People who had worked on the study were saying the results were not reliable (Bryant 1993, Caines et al 1993). These claims were being countered by the principal investigators (Miller et al 1993a, 1993b). To make matters worse the material presented in the local media was confusing.

This raising of public awareness resulted in the House of Commons striking a Sub-committee of its Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women to consider breast cancer (Greene 1992). This Sub-committee sat for the period just before the interviews were completed. It heard testimony from experts, special interest groups and the general public.

One result was the establishment of the Canadian Breast Cancer Research Initiative\(^{148}\), which included the convening of the National Forum on Breast Cancer (Report on the National Forum on Breast Cancer 1994). This Forum included representatives from all the major interest groups, and in particular women who had had a diagnosis of breast cancer.

\(^{148}\) This research initiative was for $25 million to be allocated over five years (Ottawa Letter 1992).
Locally there was the formation of the British Columbia Chapter of the Canadian Breast Cancer Foundation, a group that organized a number of large fund raising events, as well as informational and awareness events. There were also other fund raising events which targeted breast cancer.

Most of these local and national events were reported in the local media. This activity began a public discourse surrounding breast cancer which some of the participants contributed to and were aware of.

What I have found interesting is the fragmentation in this developing discourse. The discourse includes both the many different concerns discussed previously and the major rhetoric of the older, more established, discourse on cancer.

Before going on to discuss this developing discourse I review the established discourse on breast cancer. The discourse is a commonly heard discourse and is probably best exemplified by the Canadian Cancer Society’s slogan "Cancer can be Beaten."

Patterson (1987) outlines a social historical review of the development of cancer research and government policy on cancer research and prevention in the United States. Traditionally the promise of cancer research has been that a cure for cancer will be found; it is just a question of finding the resources to put into research and treatment.

This sentiment has been maintained in many of the fund raising efforts of organizations such as the Canadian Cancer
There were a number of participants who also participated in this discourse.

"It really is [hard to understand], it's sort of, I don't know, just hope that they get to the bottom of it one day and find a cure and one they get a, ah, get immunized against it and that's it. (laughs) That would be nice." (Leslie)

"I feel they certainly, ah, have researched it a lot and they seem to be making progress with the amount of people they have cured."

I: "So you feel there's progress being made?"

"Oh yeah, I felt that, you know, I guess, you know, since the Terry Fox run and the, you know, all this money that's being accumulated for them, it must be doing some good. I, I think cancer can be cured, not that I know anything about it (laughs) but it's, you know, stands to reason that they're, they're working on it so hard that, that something should come out of it." (Jane)

This traditional discourse does offer hope for the future, that there will be a cure, even if not in our lifetime. In this way this discourse is similar to the discourse of hope learned during diagnosis and treatment which focuses on the possibility of getting rid of the cancer.

The construction of hope, at both the individual and the societal level, is a major theme in the cultural construction of cancer. In both these instances the construction of this

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149 Events sponsored by the Canadian Breast Cancer Foundation, British Columbia Chapter including a fund-raising run called "Run for the Cure". The use of titles such as this contribute to this traditional discourse on cancer.

150 Terry Fox was a young man who started a fund-raising run across the country after he had been diagnosed with cancer. To continue his efforts every year communities across the country hold fund raising runs.
discourse helps maintain the status quo in the health care provision and health research systems. The discourse implies that what is needed is more resources rather than any fundamental change in thinking or in allocation of resources.

The developing discourse concerning the politicization of breast cancer is also present in the narratives. In most cases this discourse covers many different subjects.

The first theme is participants indicating that they did not like some of the interpretations of the risk of breast cancer. The area that is problematic is the concept of self-responsibility for getting cancer and in the treatment of cancer. Included are the "cancer personality" and the individual having some kind of control over the growth of the tumour, such as through being under a lot of stress or having a negative attitude.

"Like I don’t know, like I always used to, I wondered what some people would say is you bring it on yourself sort of thing. ‘Cause you’re all stressed out and I thought, ‘Oh, it’s not true. Do I really?’ But that makes me very sad to think that I would, somehow I contributed to my own, . . ." 

I: "So you have actually heard that being talked about?"

"Yeah, and that made me feel like, like the whole thing was blame the victim again." (Amy)

"Oh I actually had a fellow who I met before and had met through business and his wife had had cancer, so he somehow got word about my situation and he phoned and we were talking. He said, ‘This is really unusual, you don’t seem to have a cancer personality.’ Yeah, exactly. I said, ‘What do you mean?’ And he went on telling me about all these, you show me any twenty women in the world who haven’t had trauma in their past ten years of their life or who, I mean. Or another group who have had anxiety and stress. I couldn’t believe that, I find that very disturbing." (Mary)
The second theme participants discuss is the idea that there is not enough resources or money being spent on breast cancer.

"I think that, ah, the Cancer Clinic is good, they’re doing a lot good, good things but you know as they say more women die of breast cancer and cancer and yet they’re not putting near as much money towards research as they are to AIDS. And not near as many people die of AIDS. And yet they’re pumping money into it, into research, is that because it’s women and men are in charge of... that’s what people imply. It’s the men that are getting the AIDS and the women are getting breast cancer and, and, ah, the people who dole out the money are, you know, because cancer has been around for so long, I can’t, to me I really think, ‘Why haven’t they found out more about it? ’That’s what I really think. They’ve been giving money to cancer for how many years, ever since I’ve been aware yet why hasn’t, why can’t they find out more?" (Jean)

"You know that, ah, one day they’re going to come along with something, you know, I mean, I sometimes feel that they’re fighting AIDS more than they’re fighting cancer which has been around for a longer time and is, ah, more common in everyday people, you know. I grant it AIDS is too, but, umm, you sometimes think that they’re dwelling more on that problems than what they are on the cancer problem and it kind of gets annoying at times, you know. But, ah there again if they come through even with a, a type of cure for that, you know, ah, it’s got to be someday, you know, I think, you know with the money that’s spent on research and, ah, it will be, it will be one day, I, I believe that. Maybe not in my time, but say in our grandchildren’s time so I mean at least if it’s coming that’s, that’s a big thing." (Leanne)

The third theme discussed is a concern that research and services are inadequate or that funding is going to the wrong areas. An example is Catherine’s talking about how she had to wait for the use of the arm pump at the Cancer Agency. Another area of concern is the expense and lack of quality of prothesis.

Some of the participants are concerned about immigrant and poor women not having adequate access to information and services.

"I think there is, umm, do people who, I don’t
know about socio-economic groups, ah, whether those who have less access to reading material, umm, whether the number might be greater who perhaps, umm, let the cancer go too long because their reading material is not getting to that socio-economic group. Is this, is that part of your research? I don’t know, because reading material is expensive, it is not, not for the average family. But for those in lower income groups, are they getting, are they getting this information?" (Eileen)

Others are concerned the message of checking your breasts and having annual mammograms is not getting to young women.

"How do we get the school system that has taught my daughter everything she needs to know about sex, above and beyond what we did at home. And every sexually transmitted disease pamphlet is up and down the hall as it should be, but they still have not taught her the normal checking and her body’s geography. Normal, like it’s wash your teeth, after your period you check your breasts. And difference, any changes go and have it checked. No, they still haven’t done that." (Mary)

There are also concerns expressed that not enough research is being done in the areas of early detection, lifestyle and the environment. These participants focus is on what may be done to prevent cancer from occurring rather than on a cure. For example, Eileen is very concerned about the environment and in particular about electro-magnetic fields.

"I feel that there is an area, and this is not your area I realize, but I think and breast cancer research they need to, there is an area where we’re are not being questioned, let’s say on certain lifestyles. And, ah, there was an excellent article that was in the New Yorker last year and it was a two part, perhaps you’ve heard about this, and it had to do with electro-magnetic fields and I think that research is not paying enough attention to this and I will tell why. When we were married we were given an electric blanket and up until, ah, we decided not to replace it, I’d say up until maybe ten years ago we slept every night under an electric blanket. . . But I think there needs to be more attention paid to electro-magnetic fields, in may case, my whole married life under an electric blanket and along with that article of a woman who did twenty years of research, you know, with people who lived
beside transformers and, ah, under power lines and
beside power lines and, I wish, no-one ever asked me at
all about my lifestyle, you know, what I ate, how I
lived, you know, did I live beside transformers, did I
live under a power line, umm, the only questions they
ever asked me was about my parents, what did they die
of?"

The fourth theme discusses concerns about the safety of
existing practices. The two practices mentioned are mammograms
and silicone breast implants.  

"Is mammography a good or a bad thing, you know,
you can see that, that some of us are getting, oh, it's
a bad thing that we shouldn't be having all these x-
rays." (Eileen)

"Yeah, I don't know, there's been a lot of press
about the, umm, silicone implants too. And so that
kind of worries me, I feel I should be doing something
to find out more about that." (Angela)

The developing discourse on the politicization of breast
cancer raises doubts about the future of cancer research and the
potential of experts to solve the problem. The focus is more on
the need to prevent cancer through research on possible causes.
This is a counter-discourse to the traditional discourse framed
in the rhetoric of "cancer can be beaten".

While the traditional discourse reinforces the construction
of hope the participants learned during the process of their
diagnosis and treatment, this developing discourse on the
politicization of breast cancer challenges the discourse of hope
by raising the potential of the unknown uncontrollable aspect of
cancer.

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151 The interviews were happening about the same time
information on problems with silicone implants was coming to
light.
F. Conclusion

This chapter explores how the participants tell their cancer story as part of their everyday social interactions. It is evident that a diagnosis of breast cancer disrupts not only the life of the person diagnosed, but also the social relationships (Bury, 1982) and the lives of those around them. Through their stories the participants either describe the repair of these social relations or try to account for the continued disruption. The cases of continued disruption challenge the individual construction of their breast cancer experience, and in doing so contradict the evolving discourse of hope.

In the section on representing self to others I reviewed the strategies the participants employ to cope with the uncertainty of having had a diagnosis of breast cancer. The main strategy is to represent themselves as survivors (Gordon 1990). They do this by employing a rhetoric of dealing with adversity, which includes being stoic, positive and getting back to normal as soon as possible. This rhetoric embodies culturally appropriate methods for dealing with any serious illness. It reinforces and contributes to the evolving discourse of hope. As well, it provides a framework around which to mobilize social relations to provide support (Bury 1982) and is an attempt to convey to others the concept of hope for the future.

Medicine and behavioural science seem to assume that the family can be counted on to support the chronically ill individual. In this research the role of the family is revealed to be much more problematic. The participants recognize that
having a diagnosis of breast cancer has the potential to destabilize their families and family relations, as exemplified by the recurring theme of the spouse who leaves a woman who has had a diagnosis of breast cancer. Many of the participants try to protect other family members by being positive and stoic. This was particularly the case with parents and children.

The participants recognize that other members of their families are afraid and try to deal with this fear by "educating" others about cancer through promoting themselves as a survivor. The response to the fear that participants found frustrating was when other family members did not want to talk about the cancer, and denied that anything was seriously wrong. Not only did they not get any support, but they were unable to share their personal understanding of their cancer. This was a challenge to their construction of cancer and to the discourse of hope.

The construction of a family history of cancer provides an interesting dimension to the understanding of cancer. There are not many illnesses that are perceived as running in families or having a genetic component. The talk about the future possibility of other family members getting breast cancer resurrects the uncertainty of cancer. In this sense it challenges both the participants’ personal construction of cancer and the discourse of hope. It can also produce a sense of guilt for those who feel they have brought cancer into their family.

This research has demonstrated the importance of family relations in the research on illness narratives. The role of the family is problematic. Women’s roles in the family as wives,
mothers and care providers have an impact on the construction of their illness narratives.

The incorporation of descriptions of other social relations into the illness narrative is just as problematic. When these social relationships, with friends and co-workers, fit with the personal construction of cancer, and friends are able to provide support or returning to work signals a return to a normal life, these relationships are positive. This also reinforces the discourse of hope, as these relations return to normal undisrupted by the diagnosis of treatment.

However, when the social relationships do not fit with the personal construction of cancer, and friends are unable to provide expected support or there is discrimination at work because of the diagnosis of cancer, these relationships are problematic. This challenges the discourse of hope by bringing to the forefront the societal construction of cancer as a death sentence.

Many of the participants participate in what I have called the cancer community. Those who do not are those who had other events going on in their lives which took precedence over the cancer, such as becoming a widow or caring for a disabled or sick spouse.

Of those who do participate in the cancer community almost all do so on the level of accessing information on breast cancer. The sources are the stories, either through media or through direct contact, of other women who had had a diagnosis of breast cancer. This sharing is "helpful", as no one can understand what
they are going through other than someone else going through the same experience. Personal experience is the basis of constructing an understanding of cancer, and contact between people who have similar experiences is critically important. No matter how empathetic a physician is he/she can not provide this type of information.

Many participants also become involved in what I have called the informal support network that operates through word of mouth. This involvement comes from a willingness to help others in the same situation (Mears 1988). Many of the participants not only want to help others but find talking about their experience is therapeutic. This type of interchange allows participants to reiterate the story of their own illness experience.

Some of the participants, usually the younger ones and those who incorporate the cancer as a point of change model into their personal narrative, use formal support groups. Many participants choose not to use these groups, some because they are unable to go due to other responsibilities or living too far away, and others because they feel they are over their cancer and do not want to sit around and talk about it.

Formal support groups work best for those women who hold a similar construction of cancer as presented in the support group. I question whether formal support groups will ever be able to provide for all women who have had a diagnosis of breast cancer, because of the multiple constructions of breast cancer which exist.
For those participants who talked about the future in the interviews there are two different discourses. It is interesting that some women incorporate both into their discussion.

The first model I have called the traditional discourse, which employs the military metaphors with a focus on a cure in the future. This traditional discourse is very similar to the discourse of hope the women learned while going through diagnosis and treatment.

The second discourse I have called the politicization of breast cancer, which raises issues with elements of the traditional discourse. It also brings into focus again the uncertainty of breast cancer, that there may not be a cure and it may not get better for women who are diagnosed with breast cancer. This is a counter-discourse to the discourse of hope, as it highlights the frustrations of living with having had a diagnosis of breast cancer.
Chapter IX - Conclusion

Throughout the analysis of this research I use the concept that much of an illness narrative is the work needed to reconstruct a personal biography after its disruption by a chronic illness (Bury 1982, Williams 1984). This reconstructive work deals with a reconstruction of self, both identity and body, and of biographical time (Corbin and Strauss 1987). As well, the reconstruction takes place within a social context which affects the way in which the narrative evolves (Gerhardt 1990, Kaufman 1988b). I also point out that overlying cultural frameworks related to illness affect the evolution of the narrative. For example, the participants' illness narratives are built around the problem of constructing a viable notion of hope for the future.

In Canadian society, cancer has been commonly portrayed as a terminal illness, as a "death sentence" (Patterson 1987). Recently, there has been an attempt to transform the meaning of cancer from a death sentence to a disease that can be survived (Gordon 1990). The narratives of women who have had a diagnosis of breast cancer include both these portrayals of cancer. Persons with other types of cancer, or other life-threatening disease, may do the same.

There is an ambiguity about survival in the cultural construction of breast cancer. This ambiguity, and the constant attempts at resolution, is central to the narratives: how to live life with the possibility of death.
The resolution of this ambiguity is to construct a viable discourse of hope for the future. DelVecchio Good (1991, DelVecchio Good et al 1990) introduced this concept from her research on oncologists. The oncologists' discourse of hope constructs cancer as survivable. They define hope in terms such as the patient's "positive attitude", "fighting spirit" and "co-operation with therapy". The oncologists maintain this discourse in their interactions with patients and with each other.

In their stories, the participants also construct hope for the future. However, through the account of their experience of living with having had a diagnosis of breast cancer, which goes beyond the treatment period, their definition of hope becomes much broader and more inclusive than that of the oncologists. It is evident that their construction of hope is modified and expanded as it is incorporated into their individual illness biography. It is important to acknowledge that the development of illness narratives for those with chronic or life-threatening illnesses goes well beyond the period of treatment and that the construction of a chronic illness narrative is an ongoing process (Scheper-Hughes and Lock 1986, Good 1994).

This is important for researchers interested in chronic illness narratives, for the easiest subjects to recruit are those who have recently completed treatment. Limiting research samples to this population will bias research results. Illness narratives at this point are strongly informed by medical culture.
A. Story of Diagnosis and Treatment

At the beginning of the participants' experience, as told in their stories of diagnosis and treatment, their discourses of hope are very similar. The participants learn the discourse through their experience of being diagnosed and treated. It is very similar to the oncologists' discourse of hope (DelVecchio Good 1991, DelVecchio Good et al 1990).

In the story of diagnosis and treatment, reconstructive work is heavily informed by a discourse on hope that focuses on successful treatment. In order for the treatment to be successful, the cancer must be defined as being treatable. This is dependent on two factors: the tumour must be small and must not have spread.

The cancer is also constructed as an entity separate from the body, so that it can be removed successfully. Some participants redefine their bodies in order to have the breast, including the cancer, outside their defined body. This redefinition of the body is the start of the process of reconstructing the body and the self (Corbin and Strauss 1987).

The treatments that follow surgical removal of the cancer are thought of as removing any "stray cancer cells" that might remain. The side effects of the treatments are described as horrendous, but also as a demonstration the treatment is working. At this point the participants incorporate military metaphors into their discourse of hope. Metaphors of the treatment describe a successful arsenal coming to their aid (Erwin 1985, 1987).
Treatment is also successful if it is administered by experts: the physicians and the institution, the British Columbia Cancer Agency. This expertise should not be ignored, for those who ignore it do not survive. This acceptance of the expertise and authority of the physicians is different from the experiences of black women in the United State (Mathews et al 1994, Wardlow and Curry 1996), and much more similar to the descriptions from Italy (Gordon 1990, 1991) and Japan (Long and Long 1982).

Inherent in accounting for the participants' own position is a process of minimalizing their cancer compared with other people's experiences. For example, participants note their cancer was detected early, which is better than for those whose cancer was detected later. They evoke the worst case scenario, and so construct their own story full of hope for successful treatment.

During diagnosis and treatment, the discourse of hope focuses on the successful treatment of the cancer. In order to incorporate this discourse into their narratives, the participants learn its important elements.

I do not suggest that the participants' sole source of information is the physicians and health care institutions. Equally important in the discourse of hope is a sense of patients' responsibility for their own care, a concept that runs throughout much of the health care system in Canada (Epp 1986). Many of the participants seek information from other sources,
including other women with breast cancer and the popular literature.

There is also no doubt that the participants know many of the concepts related to their understanding of cancer before they themselves are diagnosed with the disease. Unfortunately, cancer is a common illness, and many people have some personal experience with it, which contributes to their understanding (Balshem 1991, 1993; Gifford 1986).

At this point the discourse of hope is similar in most of the stories. This is because the participants go through similar experiences and are exposed to much the same information, and because the discourse of hope is predominant in institutional medicine.

However, once treatment is completed the participants face the first challenge to their evolving discourse of hope. If the treatments are successful, the participants are left without protection when they stop. This is the first time since diagnosis they have to face the possibility of recurrence. The participants must account for and meet this challenge. Some do this through the use of alternative therapies, such as vitamin therapy as Trisha did. Others reformulate their cancer as being over and done with, successfully treated and unlikely to recur. This is only the first of many challenges. Each challenge is accounted for, and in this process the discourse of hope continues to evolve.

Incorporated into the narrative at this point is a restructuring of biographical time. The perception is that the
more time that passes since diagnosis, the less chance there is of a recurrence. This restructuring of the passage of time is closely linked to the participants’ follow up schedule. As the time between the check ups becomes longer, this signifies the experts are less concerned about a recurrence and the participants have more hope.

During the period of diagnosis and treatment, the participants are faced with another challenge. Many of them have "scares", incidents that raise concerns that the cancer has recurred. Each scare must be accounted for ("it was only a pulled muscle") in order to maintain some coherence in the discourse of hope. The resolution of a scare also includes the reassurance from an expert, usually through the definitiveness of a technological intervention.

After completing treatment, the participants must deal with cancer’s physical consequences and continual reminders, such as edema, loss of a breast, changes in breast sensation and restricted arm movement. Some of these problems are dealt with successfully, for example by successful reconstructive surgery. Others are not, as when reconstructive surgery has unsatisfactory results. These are constant physical reminders. Some problems, such as serious edema, are also disabling and affect the participants’ day-to-day lives. These constant physical reminders are also challenges to the evolving discourse of hope.

During the story of diagnosis and treatment the participants described how they came to terms with having a diagnosis of breast cancer through the construction of a discourse of hope.
based on the premise that the cancer has been treated successfully. To be treated successfully the cancer must be small and must not have spread, and treated quickly by experts in the field. This allows for the reworking of self to become a person free of cancer.

However, even at this point in the narrative, the construct of hope is challenged by the raising of the possibility of the cancer recurring. Each challenge is accounted for and the discourse of hope revised, in some cases unsuccessfully.

This process of constructing a discourse of hope for the future is a culturally appropriate way of dealing with many different chronic problems and has usually been referred to in the illness narrative literature as dealing with uncertainty (Bury 1988, Wiener 1975, Mahr 1982). Using the concept of constructing a discourse is useful in that it can incorporate a temporal element and allows for modification of the discourse over time. In this thesis I have shown how the discourse of hope was modified as the participants were faced with challenges and was part of evolving illness narratives.

B. Rewriting Personal Biographies

After treatment the participants focus on normalizing their lives, or if normal is no longer the goal, then on a life where the cancer no longer predominates. This is a process of reworking personal biography to incorporate the breast cancer (Bury 1982, Williams 1984, Kaufman 1988a, Frank 1984). The reworking produces an account of the breast cancer. This account
links ideas of possible causes with the story of diagnosis and treatment, including the discourse of hope. It also structures and controls expectations about the future.

In this thesis I identify four schemata used by three or more participants as a framework to rewrite their personal biographies. As there are participants who do not fit into these models there are probably more variations. Variations are grounded in particular social, economic and historical context. As the context changes, one would expect the constructs to change as was the case in Farmer's (1994) research on AIDS constructions over time. One would also expect variations across geographic and cultural regions (Gordon 1990, 1991; DelVecchio Good et al 1993; DelVecchio Good et al 1994)

What is interesting in examining these models is the linkage between the accounts of the cause of breast cancer and thoughts about the possibilities for the future.

The vast majority of the participants do discuss probable causes of their breast cancer, or at least talk about the risk factors they did not have. Their descriptions of risk factors and possible causes are complex, including a wide variety of variables and links between them. For example, Amy linked possible environmental causes with the stress she was going through in her life as contributing to the development of her cancers. Most descriptions, like Amy’s, included a multiplicity of possible causes. It is important to note that these descriptions are an attempt to account for the participants’
experience in much the same way as with other chronic conditions (Garro 1992, 1994).

The most commonly mentioned risk factors are family history, age, reproductive history, diet and environmental pollution. These risk factors have been described in other research on breast cancer (Salzberger 1976, Gifford 1986, Chavez et al 1995). There is also a common idea that everyone has a predisposition to cancer, and all that is needed is a "trigger" to start the cancer growing. This concept has also been found in other research (Balshem 1991, 1993; Cornwall 1984).

This idea of a predisposition is an important element in the cultural construction of breast cancer in that if everyone has a predisposition and all that is required is some form of trigger, then that accounts for the uncertain and seemingly random occurrence of cancer. It also fits with some of the developing ideas about the immune system's role in protecting the body from disease (Martin 1994).

Each of the four schemata the participants constructed to account for the breast cancer within their personal biographies is different in the degree to which it incorporates ideas about the causes of cancer and the discourse of hope. The multiplicity of constructions of breast cancer increases the potential for conflict between constructions, leading to disruption in social relations.

The schema "Breast Cancer as a Point of Change" is probably the most familiar model, as it is found in the popular literature. It is also an extension of the discourse of hope
learned during diagnosis and treatment, but incorporates some modifications. The central premise that breast cancer can be successfully treated is still dominant; however, the participants have expanded the realm of treatment to include lifestyle changes to improve their quality of life. Some of these participants had a sophisticated discussion of possible causes of their cancer. They used this understanding to try and modify their risk of recurrence by making changes. For example, if they identified stress as the trigger of their breast cancer, they tried to reduce the stress levels in their lives.

This schema is mostly used by women in their forties and fifties. It fits with broader cultural understandings of how individuals should respond to the advent of a chronic illness (Locker and Kaufert 1988, Robinson 1990, Brodsky 1995, Powell-Cope 1995). This schema incorporates the belief that individuals can and should take responsibility for their own health and health care. For the participants, this sense of control is very empowering.

However, the schema does leave some ambiguity, in that changes are being made because the cancer might recur. This raises the possibility that the changes will fail, and there will be a recurrence. Will these participants be faced with a sense of guilt if their cancer does recur? This schema’s construction of risk, focused on the individual, does leave this possibility. It also extends the sphere of medical jurisdiction and excludes from consideration social, economic and cultural factors (Comaroff 1982).
This schema is the one endorsed by much of the treatment personnel, including social workers who run support groups, and many of the public figures with breast cancer, such as Jill Eikenberry (Landsbury Company 1988). The public presentation of one schema over the others results in a silencing of alternative constructs. I agree with Susan DiGiacomo (1992) that a critical analysis of the popular construction of cancer is desperately needed. She makes the point that medical anthropologists have tended to ignore popular biomedical literature as a source of field data that will provide a critical perspective on our own society.

Participants who use the second schema, "Breast Cancer as an Acute Illness", are constructing an account of the breast cancer as something that is over with and will not return. They do this by attributing their breast cancer to one cause that they have eliminated, or by stating that the treatment, usually a bilateral mastectomy, was successful.

This is the most black-and-white version of constructing hope; there is no grey, no ambiguity. This account offers the participant the security of being able to carry on with life without being concerned about the possibility of a recurrence of breast cancer. In a sense, this schema is an extension of the discourse of hope learned during the process of diagnosis and treatment, that breast cancer can be successfully treated if it is detected in time.

The third schema is "Breast Cancer as a Terminal Illness". The most interesting feature of this schema is the participants'
comfort with the possibility of dying. Most accept that breast cancer will recur and be the cause of their death, even if not in the immediate future.

The attribution of cause in this model is varied. Some describe in detail what may have caused their cancer and use this understanding of cause to delay a recurrence. Others, like Rebecca, are not interested in describing what may have caused their cancer. The randomness and uncertainty of the advent of cancer was enough of an account, much as found by Blaxter (1983).

This is not a common schema and is used predominantly by older women and those who had faced other serious health problems, such as Rebecca. In this schema cancer is accepted as a death sentence. The discourse of hope is present, but it is modified significantly modified to construct hope of a good life that takes advantage of the time left.

The last schema, "Breast Cancer as a Part of Life", is quite commonly used, but again predominantly by older women. The main feature of this schema is that the participants who use it have put the breast cancer behind them. Usually these women are living with a number of chronic health problems other than breast cancer, or they are dealing with another crisis in their lives, such as a seriously ill spouse or widowhood.

As might be expected in such situations, the description of what may have caused their breast cancer is not a predominant feature of the schema. The discourse of hope has been altered significantly to minimalize the breast cancer into just another health problem. The hope for the future focuses on the
resolution of other problems in their lives, not solely on the cancer.

This schema is the best example of how the context of the individual’s life affects the illness story. Other problems, such as Lisa’s arthritis, produce accounts where other concerns, such as Lisa’s concern about losing her independence, dominate concern about cancer.

Social, economic and cultural factors do affect the construction of illness narratives. By paying attention to this, we can learn about the social, economic and cultural context of those who are ill (Anderson et al 1991; Kaufman 1988b; Scheper-Hughes and Lock 1986, 1987).

In this case, older women in Canadian society still fulfil a number of roles, including that of primary care-provider for an aging spouse. They also face increasing health problems as they age. These issues are to a large degree still unaddressed. Older women who have had a diagnosis of breast cancer will be assisted by the development of healthy public policy, such as provision of respite care and housing accessible to the handicapped, as for others with chronic health problems (Padgett and Johnson 1990).

More than four schema are used by women who have had a diagnosis of breast cancer. The schema vary with age, as demonstrated by Angela’s story and other research (Oktay and Walter 1991). The schema also vary with the social and historical context in which participants experience their breast cancer. Mary’s story of becoming a breast cancer activist was
set in the context of developing activism in Canada at the time she was diagnosed, whereas Andrea's story is reminiscent of historical discourses of cancer as an immoral illness (Patterson 1987, Sontag 1978).

The multiplicity and variation of cultural schema is probably not limited to breast cancer, but exists with other illnesses as well. It demonstrates the importance of the critical exploration of the context in which illness narratives are constructed (Kaufman 1988b) and the development of theoretical perspective to integrate both macro and micro perspectives in medical anthropology (Scheper-Hughes and Lock 1986, 1987; Lock and Scheper-Hughes 1990).

C. Breast Cancer as Social Reality

As more time passes since completion of active treatment, the participants continue to modify the discourse of hope to fit it into their evolving illness account. As a result, the discourse becomes more diverse. This was also the case in the narratives of black women in the United States (Wardow and Curry 1996, Mathews et al 1994).

Part of the necessity for modifying the discourse of hope is the need to accommodate challenges to the discourse. Many of these challenges originate from the continued understanding of cancer as a death sentence in society at large.

In the analysis of the illness stories, it is evident that a diagnosis of breast cancer is not only a disruption to the life of the individual, but also to the lives of others. The
construction of an illness narrative goes beyond the reconstruction of self and biographical time, and includes the reconstruction of social relationships disrupted by the cancer (Kaufman 1988b, Bury 1982, Gerhardt 1990).

The participants are very aware of the disruption their diagnosis of cancer has on the lives of those around them, especially those to whom they are close. To counter this disruption, the participants represent themselves to others as survivors. They do this by employing the rhetoric for dealing with adversity and describe themselves as positive, stoic and getting back to normal as quickly as possible. I argue this rhetoric embodies culturally appropriate methods for dealing with not only breast cancer but any serious illness (Brodsky 1995, Robinson 1993). The use of this rhetoric reinforces the evolving discourse of hope. In addition, it provides a framework around which to mobilize social relations to provide support, and it is an attempt to convey to others the concept of hope for the future.

The participants' descriptions of how they deal with the reactions of other family members, friends and co-workers are an important part of their illness accounts. These descriptions are remarkably similar and provide insight into the conflicts and challenges the participants have to face.

The most interesting change in a relationship was that between spouses. There is a popular notion that many husbands will leave their wives following a diagnosis of breast cancer. It is not clear if this is due to the diagnosis of cancer or to
the loss of sexual attractiveness because of mastectomy. However, in most cases the participants' husbands are very supportive. Where this popular "myth" comes from I do not know, but it is prominent in the descriptions of the relationship between spouses.

Other family relationships are also problematic. Women's roles as traditional care-givers in the family mean they are constantly trying to protect their children, even adult children, by acting as normal as possible.

Those participants whose parents are alive find these relationships, especially between mother and daughter, difficult. One problem is that the rest of the family members are having to deal with the possibility of the death of their mother, wife or daughter. They understand cancer as a death sentence, and therefore do not contribute to the participant's construction of hope.

This is demonstrated by the description by those participants with children of how they want to change their children's understanding of cancer. They talk of changing the perception of cancer from that of a death sentence to a survivable disease. They seek to do this is by demonstrating to their children that they are able to survive this disease. Through this, the participants are trying to include their children in their discourse of hope.

Not all members of the family share the participants' understanding of their breast cancer, nor are they able to participate in the evolving discourse of hope. A similar
situation also happens with friends and co-workers. The relationships with those friends who share in the participants' understanding of breast cancer and who can participate in the evolving discourse of hope remain the same or improve. The relationships with those who do not change for the worse. Many participants describe their frustration at this change.

Like women who have had a diagnosis of breast cancer, Canadian society has more than one cultural construction of breast cancer. There are two conflicting constructions: one of breast cancer as a death sentence, the other of breast cancer as a disease that can be survived. The existence of conflicting constructions opens the potential for conflict. Mathews et al (1990) described how black women in North Carolina came to terms with conflicting interpretations of their breast cancer and how only some of these conflicts were ever resolved. Those conflicts left unresolved may have been a contributing factor to the women's delaying seeking medical treatment for their breast cancer until it had reached an advanced stage. The participants in this research run into problems when they come into contact with people who do not hold the same understanding as they do.

Breast cancer is not the only case of a conflict in the cultural construction of illness. Kaufert and O'Neil (1993) found a conflict in the construction of the risks of childbirth between clinicians, epidemiologists and Inuit women, which resulted in conflicts in what was considered appropriate delivery of obstetric care. In some cases the women delayed in reporting to medical personnel to avoid evacuation to the south to deliver
their child. Therefore, the recognition of conflicting constructions of illness is important, because it not only affects the individual's ability to cope, it affects the development of appropriate delivery of health services (Comaroff 1978).

Two other situations are worth mentioning in relation to the conflicting construction of breast cancer. The first is the workplace reactions to a diagnosis of breast cancer. A few participants had either faced job discrimination or were not going to tell people about their diagnosis because they were concerned about job discrimination152.

Their concern is that someone who has had a diagnosis of breast cancer will be seen as sick and incapable of doing her job (Feldman 1982, 1986; Hoffman 1989b). For those participants who have come through treatment and who perceive themselves as survivors, this is very difficult to deal with.

The other situation has to do with formal support groups run by institutions like the British Columbia Cancer Agency. In this research many of the participants did not attend support groups for a number of reasons, such as time and distance. However, a group of participants simply do not want to continue to talk about their cancer. For them, their cancer is over and done with and they want to get on with their lives.

Even Anne, who participated in a support group, found that after a certain point the group was holding her back. As the

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152 At an information fair on cancer in October 1993 I picked up a flyer about a discussion group for cancer survivors to talk about job discrimination.
participants' understanding of their cancer changes with time, as it evolves to accommodate life events and new information, they have less in common with others in the group. The support groups, especially those associated with institutions, may promote a particular discourse of hope, similar to the one learned during diagnosis and treatment. Those who develop their own discourse beyond this may find the support groups of little use.

In developing services for women who have had a diagnosis of breast cancer, it is important to recognize the multiple understandings of breast cancer (Balshem 1993, Mathews et al 1990, Wardlow and Curry 1996, Salzberger 1976, Saillant 1990). As women move further away from treatment, they will alter their understanding to accommodate their personal life experiences. Therefore, one type of service will not suit all women. Some women will not want to participate in services, such as support groups, because they are trying to end their cancer experience as a way of constructing hope for the future.

In their interactions in the everyday world, the participants are faced with many challenges to the understandings of breast cancer they have developed through their illness narratives. One last area of challenge is faced when they talk about the future, both their future and that of their family.

Many participants talk about their concern that their daughters are at a higher risk of getting breast cancer and encourage their daughters to "take care of themselves" and have regular checkups. In this way they are maintaining their
discourse of hope, for if their daughter ever got breast cancer, it would be detected early and be treatable.

However, there is also a note of concern that the participant has brought the disease, a disease that can kill, into the family. Therefore, the concept of breast cancer as a death sentence again enters their understanding of breast cancer and challenges their own discourse of hope.

Another concern about the future is the direction of breast cancer research. The traditional discourse on breast cancer research, that a "cure" will be found, reinforces the discourse of hope. However, the developing discourse on the politicization of breast cancer raises another challenge to the discourse of hope. It asks if the experts are going in the right directions in breast cancer research. It raises the question about whether a cure can be found, and refocuses the discussion on the possibility of preventing breast cancer. This evolving discourse creates the opportunity for women who have had a diagnosis of breast cancer to become politically active and provides direction for future research, much like the case with AIDS (Whitaker 1992). The acknowledgement of this discourse throws concern and doubt on the discourse of hope as originally learned by the women during diagnosis and treatment.

In this thesis I have outlined some of the aspects of the cultural construction of breast cancer. The predominant feature of the cultural construction of breast cancer is the construction of a discourse of hope, a discourse that evolves as the women's
circumstances change. This discourse has a counter-discourse in the conceptualization of cancer as a death sentence. The cultural construction of breast cancer is a constant balancing between these two different conceptualizations of cancer, a balancing act where women who have had a diagnosis of breast cancer are caught in the middle.
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Appendix I - Topics covered in 29 short interviews

- When was your breast cancer first diagnosed?
- When did the treatment end? Since then have you had any more treatment or checkups?
- How have things been going for you in the past year?
- What about your health? Do you feel back to normal?
- Has your family situation changed since you were diagnosed with breast cancer?
- Do you work? Volunteer or paid work? Do you like it? How did you friends at work react to your diagnosis of breast cancer?
- Has your relationships with friends changed since your diagnosis?
- Do you have any special friends? How often do you see them? Are they helpful? Do you help them?
- How is your relationship with your doctor or other treatment people?
- Do you celebrate anniversaries of your diagnosis or the end of treatment?
- What do you think caused your breast cancer?
- Is there anything else you think it is important for us to know?