

WRITING THE BREAST CANCER JOURNEY:  
ILLNESS NARRATIVES FROM AN INTERNET FORUM

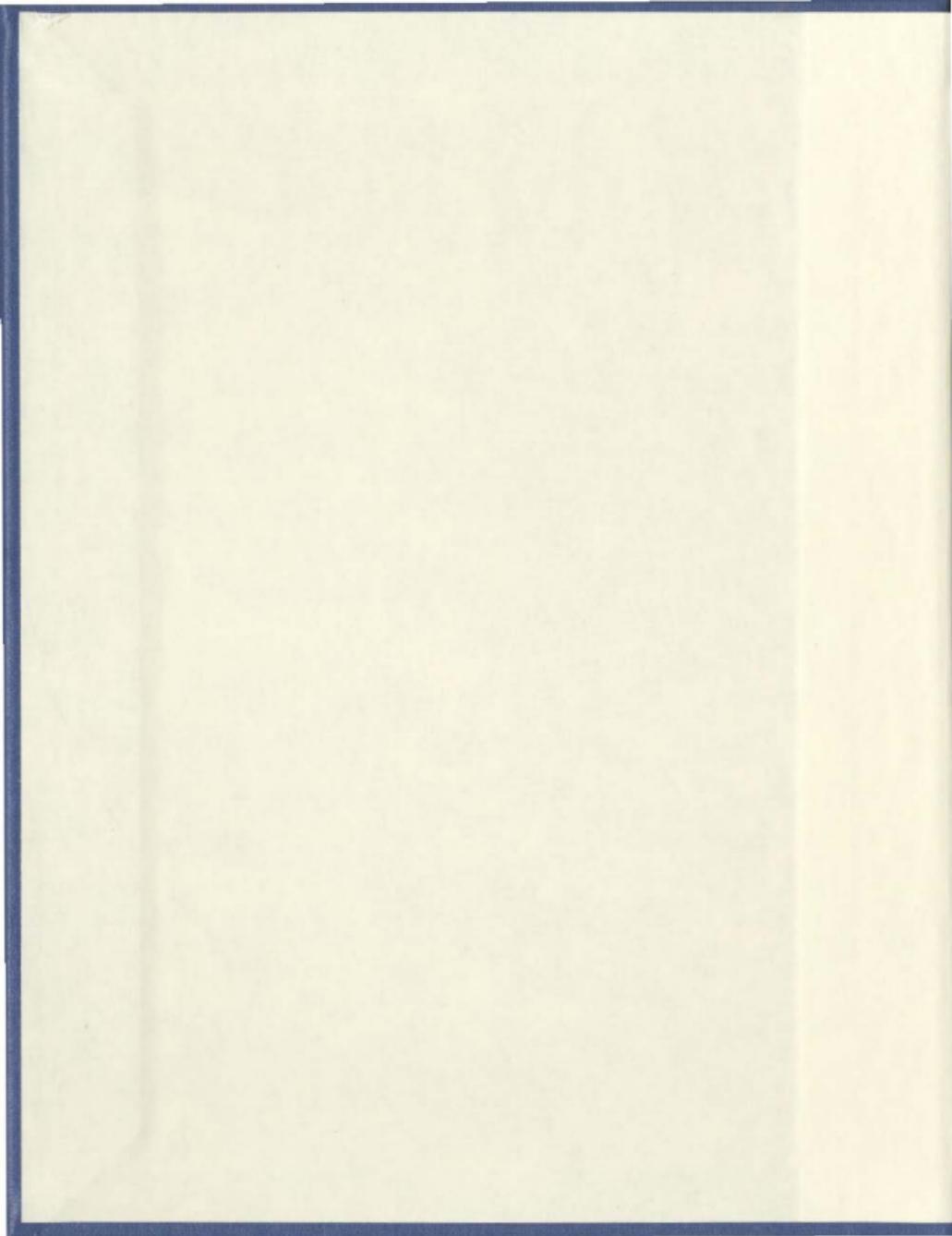
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Writing the Breast Cancer Journey: Illness Narratives from  
an Internet Forum

By

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## Abstract

This thesis is a qualitative, exploratory study of the experience of living with breast cancer, using narrative type posts to a breast cancer e-mail list. A narrative analysis methodology was used to examine these women's accounts. Through their personal writing, salient themes about living with breast cancer at different phases of the illness trajectory emerged. These include decisions about adjuvant cancer treatment, living with uncertainty, disruption of daily life and long term plans, loss of self, and realization of mortality. These narrative accounts are informed by three perspectives on breast cancer; the media and public discourse, the medical perspective, and psychosocial adjustment.

## Acknowledgements

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## Chapter One

### Introduction: Narrative Analysis and the Breast Cancer List

Breast cancer is a life-altering event that, in addition to the physical struggle it brings, leaves women striving to understand what has happened to them and their normal lives. Women with breast cancer often use the metaphor of a journey to describe their experience (Pelusi, 1997). Qualitative studies that have examined the lived experience of cancer note that only a small part of the cancer experience takes place in a medical setting; the greatest impact of breast cancer is on everyday life (Clarke, 1985). Every stage of her illness, from the discovery of a lump until years after diagnosis, influences the life of a woman with breast cancer. After the initial crisis of diagnosis and treatment, survivors must cope with uncertainty about the future, as well as changed expectations and life plans.

This thesis is a qualitative study of posts to a breast cancer e-mail list between October 1997 and February 1998. These posts took a narrative form and provided first person accounts of experience with breast cancer. I have examined these writings as illness narratives, women's personal stories about living with breast cancer. Although much work has been done in the area of breast cancer, relatively little of this is qualitative work, and I have found none that uses electronic forums or other types of written accounts in this way. My exploration of these posts is a way of gaining insight into the lived experience of breast cancer for the women who made them.

Breast cancer is a timely topic for investigation as it affects many women as well as their families and friends. Discovering a cancerous lump is a crisis event that invades

the lives of some 1 in 9 Canadian women, 1 in 8 American women. Breast cancer is the most frequently diagnosed cancer in North American women, accounting for 30% of new cases and 18% of deaths. It is estimated that in 1999, 18,700 cases will be diagnosed in Canadian women and 5,400 women will die of the disease. In the United States, 175,000 women will be diagnosed, and 43,300 women are expected to die of the disease. Breast cancer rates have been rising steadily in North America since 1984, although lung cancer has now surpassed breast cancer as the leading cause of cancer deaths in women. Increasing incidence may be attributed in part to breast cancer screening, as well as an ageing population. In Canada, the United States, the United Kingdom and Australia, breast cancer mortality rates have declined since 1990 (American Cancer Society, 1999; Health Canada, 1999).

Little is known about the cause of breast cancer; 70% of women who get this disease have no known risk factors. Breast cancer has become a high profile disease, with more money being put into research in recent years. In 1993, the American Congress approved a \$325 million increase for breast cancer research. In Canada, the Canadian Breast Cancer Initiative (CBCI) was created in 1993, a partnership of breast cancer agencies to promote breast cancer research, prevention and screening, treatment and care, as well as support, advocacy, and networking by women with breast cancer. Other fundraising efforts receive attention as well, such as those sponsored by Rosie O'Donnell, popular talk show host, and "Race for the Cure" in the United States and "Run for the Cure" in Canada, both national fundraising events. The cosmetics industry has also been active in raising awareness and money for breast cancer. Breast cancer is widely covered

in women's magazines and other media, and is readily identified by the lay public, although not necessarily well understood (Yadlon, 1997).

Referred to by its subscribers as the "breast cancer list," the e-mail distribution list is run from the Memorial University of Newfoundland. It is a forum established to enable computer-mediated communication for those interested in breast cancer with hundreds of subscribers world wide. The breast cancer list was started because one area that has remained underdeveloped is networking between women with breast cancer (Till, 1995). The Internet and telecommunication have the potential to change that (Curran and Church, 1998). These forums not only bring together a large number of women to share their experiences, but also provide an opportunity for researchers to hear their stories.

Every message posted to the breast cancer list is automatically sent to every member, and also automatically archived on a publicly accessible site on the Internet. Upon subscribing, each new member receives an automatic message with the mandate of the list that explains that it is an un-moderated list, open to researchers, physicians, patients, family and friends of patients, for the discussion of any issue relating to breast cancer (see appendix A). Membership fluctuates constantly, but this list sustains a large number of members. During the period of my research there were up to 800 members. The majority of members are from the United States, and there is also a significant proportion in Canada. People have also logged on from at least 25 other countries (Sharf, 1997). In February 1998, the list of current subscribers showed that 501 members were from the USA, 34 from Canada, and 7 from Great Britain, with a number of other countries represented by one or two members.

Because the list has such a large membership, it is very busy, and the list can accommodate up to 150 messages daily. The majority of the many subscribers typically assume the role of “lurker”; one who generally reads without posting. A small proportion of the list membership, posts regularly, sometimes several times a week, depending on the topics being discussed. The names that appeared repeatedly during the period of my research, those that posted regularly, did not exceed 20% of the total list membership. By virtue of the medium, the list is available to its subscribers 24 hours a day; members can post and read messages at any time. The list differs from traditional face-to-face support groups. Support groups are very small compared to the membership of the breast cancer list, and because of that not as varied. “Because they are comparatively small, self-help groups may lack members who share a person’s specific diagnosis or social circumstances” (Galegher, Sproull and Kiesler, 1998). Electronic forums are not comparable to face-to-face settings as they offer a new way of learning about the experiences of other people, and interacting with them. With lists such as this one, women with very little mobility can still log onto their e-mail account and exchange words with others like them (Sharf, 1997).

When I first subscribed to the breast cancer list in the summer of 1997 I was interested in writing a thesis in the area of women’s health. I knew immediately that what I was looking at, the dozens of messages that piled up in my e-mail in-box daily, were sociological data (Franzosi, 1998). I came to the list, as many of its members do, looking for information. What I was struck by, however, was the story telling that took place on the list, and the warmth and creativity of its members. A majority of messages posted to the list are from women actively coping with breast cancer, or surviving. These women

talk about their daily lives, about the agony of making decisions, about their family and friends' reactions to the disease. They commiserate about their relief over a clear check-up, or waiting for results, and they make jokes about the many discomforts and humiliations inflicted by cancer treatment. Both the largest and smallest aspects of life with breast cancer and life after breast cancer were there. These are the kinds of posts that I have used in this thesis.

### *The Study*

This thesis analyses a sample of narrative type postings to the breast cancer list between October 1997 and February 1998. By these I mean first person accounts of life with breast cancer. It is increasingly recognized, in medicine as well as in social science, that patients have their own understanding of their illnesses, which may or may not correspond with medical interpretations. Illness narratives are about personal meaning, about how illness changes a person's life story, and transforms who they are (Frank, 1995).

Storytelling is a familiar and enduring way of organizing information and structuring experience. It is natural to resort to a storytelling form when sharing experience. "Much of our cognitive and emotional work is performed using narrative structures: we create meaning in our lives by telling ourselves stories about our experiences" (Viney and Bousfield, 1991: 757). Although there are many types of communication on the list, including one-line questions and even recipes, a large percentage of posts are narrative style reflections on individual experiences.

On one randomly selected day during my research, a content analysis showed that 31 messages on that day were narrative type messages such as I am using here; first person accounts of experience with breast cancer. Thirty messages were one-line questions, queries for information, or purely informative messages with no reference to personal experience, by any list member. Three messages were forwarded reports of new studies, 3 were addresses for web sites, and 2 were humour. Eighteen were off topic or trivia. On that day, men posted eight messages, and 9 messages were from people with some professional expertise in medicine or breast cancer, some of who were also men. Sharf's content analysis showed that about 20% of the list is male, including some men with breast cancer (1997). Thus, on any given day, there are a substantial number of posts from women who have experienced breast cancer, relating some aspect of their experience. These are the posts that I focused on in gathering data.

I will quote here from 33 women who gave me their permission to use specific quotes that I gathered during my research period. Of these women, 5 posted between 2 and 10 times during my research period; fourteen posted between 11 and 20 times, 6 posted between 21 and 30 times, 6 posted between 41 and 100 times. Two posted more than 100 times during that period.

The list, according to its members, is a place for self-discovery, group support, sharing information and views and documenting daily experience. Posts to a newsgroup or e-mail list such as this one can reveal much about the author's creation of meaningful experience, and how they cope with grief, loss, and transition. Before the Internet and computer-mediated communication, this kind of personal writing was found in diaries and journals, which provided an ongoing record of experience and perspective.

Here on these pages I am spinning my thread. And a thread does run through my life, through my reality, like a continuous line... It's not so much the imperfect words on these faint blue lines, as the feeling, time and again, of returning to a place from which one can continue to spin one and the same thread, where one can gradually create a continuum, a continuum which is really one's life (Etty Hillesum in Wylie, 1995).

Published diary accounts by women are scarce, and access by researchers is limited, which is part of what makes the breast cancer list unique as a research site.

Some scholars are suspicious of the Internet, and there is a debate as to whether computer-mediated communication can constitute authentic social interaction, and whether virtual communities are actual communities (Jones, 1995). The potential for anonymity and transience, and the lack of embodied presence on the Internet contradict our notion of meaningful interaction (Baym, 1995). These concerns are more pertinent to other types of virtual forum however. The breast cancer list appears to be the kind of computer-mediated communication that supplements real life interaction.

On the breast cancer list, contributors generally use their real names, which can often be confirmed in their e-mail address. Those who use nicknames come to be known to list members under that name, creating identifiable personalities. Some list members put their diagnosis in their signature file. Sharf (1997) notes that list members refer to the list as an actual *place* of social interaction. It is also important to note that although it is a disembodied medium, the topic of conversation centres on the body and embodiment. This list has a yearly meeting of list members. In 1997 this meeting was in Chicago, and in 1998 it was in Calgary. A number of list members have made the effort to meet other subscribers who live close to them, and then written about these visits to the list at large.

“The more important electronic groups are to their members, the more engaged their members will be in group discussions” (McKenna and Bargh, cited in Galegher, Sporoull and Kiesler, 1998: 506). On the breast cancer list, the sheer volume of mail requires a significant time commitment. The intimate, conversational style of writing in electronic forums like this one is also striking (Baym, 1995). Participants use “emoticons” (symbols such as the smiley face) and colloquialisms to mimic real life conversation. The list members also work hard to keep the list a place for sharing, and irrelevant messages, such as *spam*, (unsolicited junk e-mail) are very actively discouraged.

I would also suggest that frequency of posting is an indication of the list's importance to individual members. The archives show that for the first week of January 1998, a randomly selected week during my research, there were a total of 639 messages. I identified 1 person who posted more than 20 times that week, 1 who posted 20 times, 8 people who posted between 11 and 15 times, 31 who posted between 5 and 10. The rest of the list subscribers posted less than five times that week, of those who posted at all. People become involved in more than one thread of conversation at once, which is why some people post so frequently. Most members also go through phases where they post a lot, because they can contribute a lot, and phases where they don't post very much.

In her research on how this list provides a resource for women with breast cancer, Sharf (1997) noted that ethnicity and socio-economic status are factors infrequently disclosed within messages, and there may be political, demographic, and psychosocial biases in the membership. Because the list requires computer access and the ability to use e-mail it is not accessible to everyone. Many of the list members are self professed

“information seekers” and the nature of the list and its information/support mandate mean that members are actively involved with coping with breast cancer, a characteristic that is not representative of all women with this disease (Spiegel, 1997). Thus the views expressed on the list cannot be generalized to the larger population of women with breast cancer. In addition, because there are a large number of *lurkers* on the list, the views expressed there cannot be generalized to the whole of the list membership either.

## Theoretical Perspective: Sociological Use of Narrative

### *Illness Narrative and Identity*

Interpretive sociological methods are most appropriate for an examination of how people create meaning through social interaction and within particular social contexts. In the sociology of health and illness, these methods helped develop analyses of how illness is socially constructed and socially mediated, the symbolic meaning of illness, and illness and identity (Clarke, 1990). They have marked a shift away from the study of clinical practice and the experiences of doctors, to a focus on the patient’s experience of suffering (Hyden, 1997).

Hyden notes that the popularity of this type of research is relatively recent (1997). Traditionally, medicine has defined illness, and sociological analysis initially adopted biomedical and institutional perspectives on illness. The sociological study of illness experience, particularly that of chronic illness, was pioneered by Anselm Strauss. In *Chronic Illness and the Quality of Life*, Strauss (1975) examines the subjective experience of being ill, how people manage illness, and how it affects their lives.

Kleinman distinguishes between *illness* and *disease* to describe the incongruity between the medical and personal realities of sickness. Illness is meant to "conjure up the innately human experience of symptoms and suffering," while disease is the problem from the practitioner's perspective (1988:5). Ideally these two perspectives complement each other. However, all those who are dependent on medicine and medical management experience the "medical gaze," an institutionalised, dispassionate view of illness. Those with a serious, chronic illness will become aware of this in the course of their medical treatment, and come to see their own disease, in part, through this perspective (Shilling, 1993).

Chronic illness is not limited to physical problems, but creates dissonance and disruption in individual's lives, clearly separating before and after. "Illness represents a distinct way of being in the world- a way of being which is characterized not simply by bodily dysfunction but by a concurrent disruption of self and the surrounding world" (Toombs, 1992:127). We perceive illness as an assault on our identity. It is when we are ill that we experience our bodies as most distant from our *selves*; the synthesis between body and self is broken. Medical appointments and tests, aches and pains, surgery, and immobility all make the body and health central in one's consciousness, displacing normal life. Charmaz notes that loss of self is a particular type of suffering that accompanies chronic illness. "Chronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new ones" (Charmaz, 1982: 168). A forum like the breast cancer list can potentially help women to manage these feelings of loss.

Bury (1982) conceptualized chronic illness and the chaos that it introduces into everyday life and plans as *biographical disruption*.

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 a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others (Bury, 1982:169).

Narrative reflections on illness will incorporate the time before, the onset of the illness, the disruption and crisis caused by it, as well as a resolution (Williams, 1984). When an ill person talks about her illness, all aspects of it are portrayed through the lens of her own personal history. Diagnosis, tests, symptoms and treatment are never simply facts, but are all drawn into the individual's story. The ill person puts her own experience at the centre of her narrative, making links between her illness and resulting changes in her lifestyle, work, relationships, and priorities. While resolution is true of many published accounts of illness, other accounts such as diaries or letters will be more fragmented and convey feelings of chaos, disconnection, and living in limbo (Hyden, 1997).

According to Williams (1984) the function of narrative to someone with a chronic illness is that it enables them to reconstruct their biography and make sense of what has happened to them. In the face of any loss we are put into a transitional situation, in which we must adapt our former, common sense perspective on the world, as it no longer fits our reality. This process is not limited to chronic illness, but in the case of acute illness it would be much more short-lived, with an expectation to return to one's former state of health, without any prolonged interval of illness, or chronic health problems.

Hyden (1997) notes that narrative and identity have become closely linked concepts, and that narrative has become a proxy for identity in illness narrative research. Other narrative research has examined the impact of illness on a person's sense of self (Garro, 1994; Riessman, 1990; Vinney and Bousfield, 1991; Williams, 1984). In her analysis of people suffering from temporomandibular joint problems (TMJ), Garro (1994) found that the lack of recognition for their condition led patients to struggle to understand their illness as a physical, not a mental problem. Riessman (1990) has examined illness as it relates to the presentation of self. Because stories pull the listener into the teller's point of view, they are a means of gaining an inside understanding of how they experience their social world (Riessman, 1990).

Research that uses women's voices, their own understanding and world-view, is a goal of feminist research. Feminist research attempts to produce analyses grounded in women's life experience, to make women "the subjects of the sociological act of knowing" (Smith, 1987). It puts women at the centre of social inquiry, using either traditional or innovative methods that will address questions of women's knowledge and women's experience (Maynard 1994).

## Methodology

“Story telling, to put the argument simply, is what we do with our research materials and what informants do with us” (Riessman, 1993: 1).

### *Narratives*

There is no one definition of narrative, or method of narrative analysis. A broad definition of narrative is that it refers to talk organized around consequential events (Franzosi, 1998). It is a first person account of experience. Narrative is not the response produced in a structured question-and-answer exchange, but involves the telling of a story. What a narrative tells us is not only what has happened, but also how the narrator understands what has happened, and the meaning they have created out of it. Narrative is not about historical accuracy, but rather the point of view of the person telling. For the sociologist, narrative offers a glimpse into subjective experience, and what life means to the narrator at the moment of telling (Riessman, 1993).

### *Narrative Analysis*

The narratives I have used in my thesis developed in the context of exchanges on the breast cancer list. I introduced myself and the research topic to the breast cancer list, but I did not participate in the discussion. My exchanges with list members were limited and were all private ones, with the women who agreed to be quoted (See appendix B). At that point I developed a dialogue with these women, and they often took the opportunity to elaborate on what they had already posted, or comment on my research topic.

Fonow and Cook (1991) describe access to a site where the relationship of researcher to subjects is less prominent than that of subjects with each other, as the research potential of an *already given situation*.

Because the exchanges took place between list members, I had no role in directing the material on the list. One characteristic of the list is that a member can respond immediately to an issue that has presented itself, such as waiting for test results, their first treatment, daily challenges and overwhelming emotions. These women can write about what they are experiencing at a particular moment in time. Thus, these narratives have the potential to provide new insights, new themes or emphasis to existing narrative research, which is often done using interviews. While they are short and often fragmented, e-mail posts have immediacy and intimacy even unstructured interviews may not produce.

Labov's (1982) paradigmatic model of narrative analysis is the departure point for most narrative analysis. Labov defined narrative as matching a verbal sequence of clauses to a sequence of events. The temporal ordering of these events is the most important criteria of a narrative because it implies causality to events; what he labelled a '*complicating action*'. The complicating action is an elaboration of the focal point of the story, which is introduced prior, during the *orientation* that introduces the people involved and the context. The *abstract* is the starting point of the story, the reason the story is being told. After the complicating action, stories generally conclude with a *resolution*, which may be achieved through a *coda*. The coda signals the end of the narrative and brings the narrative back to the present. Not all these elements are

necessarily present in a narrative, but these features describe a complete or perfect narrative form (Riessman, 1993).

Narrative analysis is concerned with representations of experience, which then are represented by the researcher (Riessman, 1993). The researcher aims to invoke the experience of the narrator, while adding layers of analysis. However, a text is not a window on reality, but one person's truth, at one point in time. Likewise a narrative analysis should be evaluated not for historical accuracy, but faithfulness to the story being told. As Riessman notes, the object of analysis is not people, but their stories.

Narratives are interpretive and, in turn, require interpretation: They do not speak for themselves or provide direct access to other times, places, or cultures. Our analytic interpretations are partial, alternative truths that aim for believability, not certitude, for enlargement of understanding rather than control (Riessman, 1993: 23).

This method is not generalizable beyond the narratives used, and there are always alternative readings on the narratives being studied. Riessman (1993) makes a subtle distinction between trustworthiness and truth. If the interpretation is reasonable and convincing, and if it is the best fit to informants' accounts, then it is trustworthy.

### *Creating Narrative Texts*

Narratives used in sociological analysis always become text, either because narrators wrote them down originally or, more often, because researchers work from written transcripts of oral interviews. Using e-mail messages as narratives solves some of the common problems in narrative analysis. In transcribed interviews the researcher must decide whether they should include every word and pause just as the respondent said them (Franzosi, 1998; Riessman, 1993). Unstructured interviews may be meandering,

and include long digressions or features of speech that are difficult to read. This leaves the interviewer to make a decision as to whether she should preserve the integrity of the narrative, or edit out what is irrelevant to the study.

E-mail messages are much shorter than a transcribed interview. They don't contain lexical sounds such as "mhm" or pauses. E-mail is already structured into discrete texts with parameters. The subject line gives a good indication of the topic of the message, although this is not always the case. Sometimes long threads of conversation will develop by members following up on an original message, and the subject heading remains the same while the conversation takes different turns. Some messages are also long, and may cover a variety of topics. Nevertheless, e-mail messages/narratives on the breast cancer list contain some structure by virtue of the e-mail format.

### *Sampling and Data Analysis*

Developing a methodology to deal with the vast amount of material on the breast cancer list required some innovation. My simultaneous goals were immersion and data reduction. I spent five months on the list, as much time as possible so that I would be sensitized to the list culture, and the ebb and flow of discussion over the long term to be better able to select themes for analysis. I used features of e-mail to sort messages as I developed categories, by saving messages on similar topics in labelled folders in my account. At this stage of my research folders in my account included "coping", "survival", "hair", "lifestyle", "diet", "decisions", "treatment", "doctors", "pain", "symptoms", "metastasis", "suicide" and "inspirational poetry." Some categories were closely related, and could be linked to issues that recurred consistently on the list.

In keeping with qualitative methodology, my analysis was concurrent with data collection (Ely, 1997). My emphasis was greater on collection of messages at first, and then shifted to the development of themes, which determined the direction of further data collection. Again, features of the list helped me in this. Because the list is archived automatically, I was able to review entire months worth of messages, to compare with the themes as I developed them. As my analysis progressed I worked to address discrete themes as they emerged on the list.

As Kasper (1994) noted in a discussion of qualitative research on breast cancer, the first level of analysis takes place with the women themselves, in that they chose what aspects of their experience to articulate. The final phase of this qualitative research was the selection of exemplary narratives to illustrate the themes I had developed. Exemplary narratives contained thick description of personal experience, and crystallized an issue as it emerged on the list. Most of the women I have quoted were regular posters during that time, and because of that well known to the list as a whole. Regular posters often started threads of conversation, and others would address replies to them. I present entire posts in the chapters that follow whenever it makes sense to do so, but in some instances a part of the post was all that was needed.

### *Research Ethics*

While the accessibility of the Internet makes it exciting to researchers, clear ethical guidelines have yet to emerge for Internet research (Till, 1997). There is no standard approach to ethics when it comes to using data from Internet groups. Some researchers have argued that the central issue is whether the material is considered

published (Till, 1997). If they are published, researchers could use posts so long as they were attributed to their authors.

In contrast, Klemm and Nolan (1998) argue that whenever someone is designated as a research subject they must be protected as such, and this also applies to the Internet. Following this approach, I got permission from all the women I quoted using an electronic consent form (appendix B). In it I said I would protect their confidentiality as much as possible, given the public accessibility of the list's archive. I felt it was important to take this ethical approach, as it is evident from the messages posted to the list that women there are addressing the list only, not a wider audience. My proposal for research was reviewed and approved by the Faculty of Arts Ethics Committee at Memorial University (appendix C).

### *The Research Narrative*

Reissman has cautioned that her narrative retelling is "an imaginative and interpretive enterprise.... Readers should keep this point in mind as they construct their interpretation of my interpretation of (the narrator's) interpretation of his experience" (1990: 1196). Elsewhere she has argued that in narrative research, validity comes from coherence and plausibility (Reissman, 1993). Are the readings of narratives, and analysis across narratives, a good fit? I will address the issue of validity further in my conclusion. It is important to note at the outset that my analysis is not the only reading of these posts, but one that is true to the themes as they emerged at that time. These themes describe some major issues in living with breast cancer as articulated by women posting to the list, and perhaps even for the larger population.

Other research gives an indication of whether this work fit in with and possibly expands on other, more representative accounts. Chapter two will examine the social and psychological context of breast cancer, as it is described in existing literature. I also briefly review the medical information that women on the list have about their disease, and the larger cultural perspective on breast cancer. These personal, psychosocial, medical and cultural dimensions of breast cancer are all evident in these narratives, and all play a part in the breast cancer experience.

The analysis that follows roughly traces a trajectory that begins after diagnosis and surgery, with choices in adjuvant treatment. By the time women become regular posters on the list, they are generally past the immediate period of diagnosis, and possibly surgery as well. Choices about adjuvant treatment, the treatment that follows surgery, is a consistent thread on the list, one that draws many posts based on experience. When questions are posted about treatments like chemotherapy, radiation and hormonal therapy, members will typically preface replies by saying "I can only tell you what my experience was...". How the personal context of decision making about this treatment, shapes the meaning it has for women, is the subject of Chapter three.

Overlapping this treatment phase, and the time after treatment, is the disruption of normal life caused by illness, and problems integrating cancer with daily life. Chapter four addresses the changes in daily life experienced by these women with breast cancer, and the changes in their sense of self. Everything, from scheduling in medical appointments to handling friend and family reactions, creates new challenges. The uncertainty experienced by breast cancer survivors, both on a daily basis and in terms of the future, must be integrated into everyday life.

Any breast cancer diagnosis brings with it a realization of mortality, which women with breast cancer may confront repeatedly throughout their illness and its aftermath. In Chapter five, I look at how those with advanced cancer manage their illness, and in particular, how they approach time. By shifting their emphasis from the long term to the present, women on the list have dealt with issues such as medical management, family, and spirituality. In the conclusion I review the contribution the list makes to sociological understanding of breast cancer, benefits and limitations to this work and its approach, and directions for future research.

## Chapter Two

### Three perspectives on breast cancer: cultural, medical, and psychosocial adjustment

“Discourses on medicine, health, illness and disease construct realities in ways that are often taken for granted and invisible” (Lupton, 1994: 73).

Illness narratives are about the self, an expression of individual illness experience, but narratives are created in a cultural and societal context. In *The Illness Narratives*, Kleinman conceptualized narrative in a broad way that encompasses the lived experience of illness, and how illness is culturally shaped. “In the context of a chronic disorder, the illness becomes embodied in a particular life trajectory, environed in a concrete life world. This web of cultural and personal meanings means that an illness can only be understood in the context of the person living it” (1988:30). The cultural and symbolic meanings attached to illnesses mediate an individual’s experience, and they construct meaning from the interplay between their illness and their world.

Cancer is not simply a series of related experiences including diagnosis, surgery, sickness and recovery. A woman already has a cultural script for cancer, which is different than that for other illnesses (Sontag, 1978). Prior to diagnosis, all a woman knows about cancer may come to her through media and other public discourse. Also, because breast cancer affects a part of a woman that, according to our culture, is part of what makes her a woman, breast cancer is experienced as different than other kinds of cancer (Lanellier, 1998). On the list there has been discussion of television specials about breast cancer, and how they portray women with breast cancer. Notices about breast

cancer related art shows in major cities are often posted to the list. When the television sit-com character “Murphy Brown” was portrayed as having breast cancer, this generated much talk on the list, and some list members re-lived their diagnosis through this character.

Medicine is an integral part of a woman's understanding of her illness as well. On the breast cancer list, there are discussions about medical studies and what they could mean to women who have the disease now. There is discussion of participation in clinical trials, and medical theories about cancer. List members frequently put the date of their diagnosis, the stage of their tumour and other details about the cancer, and the treatment they received, in their signature file or in the text of their message as reference points. For example, “diagnosed with Stage IIIa in 4/90, 7cm tumor and 11 positive nodes, ER&PR+. Surgery, then 3 weeks later started 8 CMF chemo and 30 radiation treatments, then on to Tamoxifen in late 1990.”

Personal narratives can fill in the gaps between the ill person's reality and the biomedical perspective, but medicine is a part of any individual's experience of breast cancer. Women with breast cancer may even challenge their position vis-à-vis medical authority, yet they will still use medical terms to talk about their illness, and for that reason a sociological discussion needs to address this medical perspective.

Finally, those list members who are involved with support groups or are interested in the support literature may be aware of research about adjustment after breast cancer diagnosis and treatment. Others may not be, although they have likely experienced problems, and perhaps discussed them on the breast cancer list. The psychosocial literature on breast cancer focuses on how women adapt to breast cancer.

Oncology research reflects a trend toward the provision of more comprehensive assessments of patient functioning, that incorporate subjective, multidimensional measures of health-related quality of life in addition to disease and treatment related factors (Bull et al., 1999: 47).

This literature focuses on quality of life issues and different dimensions of well being, styles of coping, and social support. The focus is on individual experience, and work in this area indicates the salient issues in living with breast cancer.

Using the breast cancer list as a research site brings out the individual, medical and cultural aspects of breast cancer. Narratives used in this thesis were written in the context of exchanges between members of a supportive group, and as such often capture women's experiences with breast cancer at specific moments in time. The perspectives reviewed in this chapter are all helpful in understanding these posts.

## Media and Popular Discourse

To understand the experience of breast cancer and its meaning to the individual, the potential influence of cultural meanings must be understood. Earlier research on cultural perceptions of cancer emphasised stigma (Goffman, 1963; Strauss, 1975; Sontag, 1978). Recent research shows, however, that the social isolation experienced by those with cancer is likely due to reduced social activity, rather than stigma (Kessler, 1994). The suggestion that those with cancer are no longer as stigmatized as they once were is supported by the considerable media coverage of cancer, particularly specific types of cancer, including breast cancer (Lantz, 1998).

Cancer has been compared to AIDS or heart disease, in terms of cultural differences (Clarke, 1991; Sontag, 1978; Weiss, 1997). Weiss notes that the public's negative attitude towards cancer is probably related to broad vulnerability, beliefs about difficulties treating and preventing it, and to its high mortality rate (1997: 457). AIDS by comparison, is associated primarily with a minority group. Heart disease is seen to be less threatening and more treatable than cancer. For those who recover from heart disease, it may not create profound life changes. In contrast, the respondents in Weiss' study portrayed cancer as a transforming experience, one that resulted in permanent change.

A critical reading of the metaphors used to describe cancer offers insight into its cultural meaning. Cancer is portrayed as a silent, insidious disease- one that corrupts from the inside. As Sontag (1978) has argued, the use of militaristic language in describing cancer has become so pervasive it is almost impossible to talk about it in any other terms. The words *battle* and *fight* are invariably attached to discussions of cancer and cancer treatment. The word "cancer" in western culture is so powerful that many prefer to use euphemisms to describe it (Clarke, 1986).

The media is an active participant in the creation of public discourses and meanings around cancer, and a powerful influence in how we understand the disease. Several studies (Clarke 1986,1991; Lantz, 1998; Lupton, 1994) have analyzed coverage of cancer in the print media. Lupton (1994) and Lantz (1998) have looked specifically at breast cancer coverage in magazines in Australia and the United States respectively, and Clarke (1986,1991) did similar research on cancer coverage in the United States and Canada.

Lupton's (1994) analysis centred on the issue of women's lifestyle choices. In her review of Australian press coverage of breast cancer 1987-1990 she found that the dominant discourses emphasised feminine traits in ambivalent ways. Middle class career women were portrayed as a primary risk group in many articles, because medical research has linked both the pill and childlessness to an increased risk of breast cancer. Lupton noted that most pictures of women with breast cancer in these articles were of young white professional women, although that is not representative of the women that get the disease. Lupton also found what she called a *technological imperative* in print media coverage. "Drug treatment, surgery, and the use of medical technology to detect breast lesions were publicized at the expense of other, less invasive ways of dealing with breast cancer" (1994: 79).

In contrast to articles that targeted middle class, educated professional women, there was also substantial coverage of the type of attitude that helps cancer survival. Here the traditional feminine role was denigrated, and women were warned that a hostile, fighting attitude towards cancer, and being actively involved, provide an advantage, and those who are passive are less likely to survive. Both Clarke (1986) and Yadlon (1997) note that this emphasis on individual responsibility and choices effectively eclipses other information, such as environmental risks, as it does not fit the control/choice paradigm so prominent in the media and culture at large.

Similarly, Yadlon (1997) notes that because diet and reproduction choices are highlighted as carrying risk, gender roles are implicated in discussions of breast cancer. Eating well (and being thin), and putting family before a career have become part of the discourse on cancer prevention. "Discussions of breast cancer are often packaged in a

rhetoric of culpability that produces a particular kind of gendered guilt; one contracts breast cancer because one has not made the “proper” dietary and reproductive choices” (1997: 648). Through this type of coverage, the media entrenches the rhetoric of individualism, and traditional codes of femininity are reconfirmed as a defense against breast cancer.

Lantz (1998) examines the role of the media in the social construction of a breast cancer *epidemic* through increased media attention. She notes that rather than treating the emergence of breast cancer as a social problem as an objective reality, it is more useful to examine how it is created through social discourse (1998: 909). The number of magazine articles on breast cancer increased beginning in 1987, and doubled between 1990 and 1995. This coincided with the release of epidemiologic results on risk factors such as alcohol, dietary fat, exogenous hormone use and the discovery of the breast cancer gene BRCA1. Breast cancer incidence rates had already been high prior to this research, but only garnered media interest with these research results and increased mammography (1998: 912).

Lantz (1998) also notes the drama and urgency with which breast cancer stories were portrayed in the media, particularly when individuals were profiled. These stories focus on the struggle against the disease, and fighting the disease. Individual women profiled are either younger than the average age of diagnosis, or they are celebrities and high profile women.

Using younger women and celebrities in these stories is in keeping with the media’s tendency to heroize those with cancer. Weiss notes that the image of cancer is gradually changing from death, hopelessness, and “condemned” “victims” to a heroic

metaphor of “survivors” “victors” or “exceptional patients” (1997: 458). Clarke (1986) noted this in articles from the 1980s as well. “A number of articles imply that the person with cancer is both a victim of an enormous assault and a hero. Heroic efforts are attributed to the individual who is given a diagnosis of cancer. Coping with the disease is portrayed as one of life’s greatest challenges” (Clarke, 1986: 188).

Media coverage highlights those who survive against all odds (Lupton, 1994; Lantz, 1998). This discourse of hope, challenge, and beating cancer with a fighting spirit gives cancer a different cultural meaning than that in Sontag’s (1978) analysis, although one no less concerned with individual responsibility. Sontag emphasised the importance of the cancer personality. As Sontag notes, “Nineteenth-century cancer patients were thought to get the disease as the result of hyperactivity and hyper-intensity. They seemed to be full of emotions that had to be damped down” (1978: 52). In recent years, this has shifted to a preoccupation with lifestyle, and also medical technology.

Until they are diagnosed, the media may be the primary source of information about breast cancer for most women. For those who are coping with the disease it remains important (Lantz, 1998). Women may find out about medical options this way, or ways of coping, support groups, and activism. Regardless of the source of their information, medical knowledge about breast cancer heavily informs the experience of women diagnosed with the disease.

## The Medical Perspective

Only a few decades ago, doctors may not have even informed their patients that they had cancer. This has changed, and in recent years an ethic of informed decision making for the patient has developed, both in Canada and the United States. The 1993 Canadian National Forum on Breast Cancer, for example, identified as important themes increased communication between physicians and patients, support for the provision of information to patients, and shared treatment decision-making. The importance of the values and preferences of the patient are stressed by patient advocates and in models of patient participation in treatment decisions (Charles et al., 1998).

The medical story of breast cancer is one of physiology, estimates, risk factors, and outcomes. Medical science focuses on the physiological processes associated with cancer, including the stages and course of the disease, statistical estimates of survival rates, and the efficacy of treatments. The disease from the perspective of medical science is larger than any one individual.

The medical management of illness imposes a medical and physiological perspective on the ill person, but also provides them with a means of understanding their disease. It is impossible, as Bury suggests, to face illness, pain or death without recourse to medicine's codes, which are "both a resource to people in times of distress and pain and a constraint in their search for the deeper meaning of experience" (1982: 179). Those who take a proactive approach to their treatment, such as the women whose narratives will follow in later chapters, will have worked particularly hard to inform themselves of their disease, through reading and research. The medical construction of their disease is central to their narrative. Patients need the validation and sense of coherence that can be

found in the diagnosis of an ailment, and a course of treatment. It is only when medicine precludes or excludes the patient's own broader experience that it becomes problematic as a cultural model of illness.

### *Medical Understanding of Cancer*

From a medical perspective, cancer is the general term for an abnormal growth of cells, a cluster of cells that grow and multiply out of control. This is what makes cancer life threatening. Cancer causes death when invasive cancer spreads to vital organs, where cancer cells interfere with the functioning of regular cells, and eventually organ function. Breast cancer is a slow growing, (most tumours take 8 to 10 years to reach the stage of discovery) unpredictable type of cancer (Nuland, 1997).

The defining characteristic of a malignancy is that unlike healthy cells, it has the potential to go beyond its home and travel to some other place. As a tumour grows, the cells enter the lymphatic channels, and from there they enter the axillary nodes. The nodes will produce immune cells, but may not be successful in fighting the malignancies so tumour cells may pass through the node unharmed, and flow into the lymph channel that exits it. From there they may enter the bloodstream and be carried through the heart and to structures such as liver, lungs and bone. It is metastasis that causes cancer mortality (Nuland, 1997:50).

Age is the most significant risk factor for breast cancer, as the chance of developing it increases with age for all women. Thus, some young women each year will be diagnosed with breast cancer, but it is much more common among older women. Most women who develop breast cancer will do so after menopause, which puts the

majority of breast cancers in the over 40 category. Rates for women under 50 have remained steady over time, but breast cancer incidence is rising for women over 50, although mortality is decreasing. Less than 1% of breast cancers occur in males (Love, 1995; Health Canada, 1999).

Other risk factors for breast cancer include a family history of breast cancer, a history of breast cancer in one breast, a history of certain types of benign breast disease, and high levels of radiation exposure to the chest. Weak but well-established risk factors include obesity in post-menopausal women, never having had children, being 30 or more years of age at first full-term pregnancy, having an early onset of menstruation, and a late onset of menopause. Other demographic factors that increase the risk of developing breast cancer include living in an urban area, belonging to a higher socioeconomic class, and being born in North America or Northern Europe (Health Canada, 1999). About 70% of women with breast cancer have no known risk factors, however (Love, 1995).

Between 1940 and 1982, there was a steady increase in breast cancer of about 1% per year; between 1982 and 1988, the growth in the rate was about 4% per year; between 1988 and 1996, incidence rates of breast cancer have been approximately level (American Cancer Society, 1999). The increased incidence in breast cancer and the failure to identify specific causes in most cases indicate that changes in the environment that have accompanied industrialisation and pollution may be to blame (Rosenthal, 1997).

Breast cancer treatment today puts a strong emphasis on early diagnosis. Early diagnosis is often misrepresented by the media as early prevention, which can be very misleading to lay persons who lack knowledge of the disease (Lantz, 1998). Early diagnosis statistically gives a patient a better chance of survival, as it is less likely that the

cancer has spread. What is prevented is not the disease, but the event of not finding and treating the cancer before it has metastasised and become incurable. Advocacy for breast screening began in the 1980s, and since then the number of women who are screened for breast cancer has increased. This has apparently resulted in both an increase in diagnosis, and a small decrease in mortality from breast cancer. However, the majority of breast growths, both benign and malignant, are still found by women themselves (Health Canada, 1999; The American Cancer Society, 1999).

When a tumour is diagnosed, there are a number of important indicators that will help determine characteristics of an individual's cancer and appropriate treatment. These are the size of the tumour, the type of cancer cells and their degree of differentiation, whether the cancerous cells have invaded nearby blood vessels and lymph channels, and whether the cancer is diagnosed as estrogen receptive (ER) positive or negative (Love, 1995).

Well-differentiated cancer cells bear a greater chance of long-term survival. Whether the cancer has spread to the lymph nodes is established through node dissection, which is generally performed with surgery to remove the primary tumour. The number of lymph nodes that show evidence of cancer is used as an indication of the extent to which cancer cells have spread throughout the body. ER-positive cancers are at a slightly lower risk of the cancer returning, and have more treatment options because they can be treated hormonally (Love, 1995).

Pathologists describe the size of a tumour, the number of positive lymph nodes, and metastasis by a stage classification system called TNM; tumour, node, metastasis. This system uses a number after each letter to describe the patient's status. The stages of

breast cancer range from 0 to IV, each indicating the size of the tumour and the number of lymph nodes found to have micrometastasis. These stages are not precise, but each does have a general estimate of chances of survival, which decreases with each progressive stage. The 5 year survival rate for stage 0 is over 90%, while stage IV, cancer that has invaded other tissues, predicts a five-year survival rate of about 10% (Love, 1995).

Generally speaking, early diagnosis and response to standard treatment are the best indications of long-term survival from the disease. DCIS, or *In situ* tumours, today comprise between twenty and twenty-five percent of all breast cancers in Canada and the United States, and are found through mammography. These tumours have not invaded the surrounding tissues, but are confined to the duct or lobule of the breast. As a result, tumours found at this stage have the highest survival rate (Health Canada 1999, American Cancer Society, 1999). DCIS is treated with mastectomy or lumpectomy and radiation. Chemotherapy and tamoxifen are not recommended, because the risk of recurrence is very low (Health Canada, 1999). Those malignancies that are not *in situ* are termed *invasive*, meaning the cancer has spread to local tissues, surrounding tissues, lymph nodes, or other organs (Love, 1995; Rosenthal, 1997).

From a medical perspective, the treatment of breast cancer falls into two categories, local and systemic. Local treatment is surgery to remove the primary tumour, often followed by radiation to kill any remaining cancer cells in the local area, hopefully preventing a local recurrence. Mastectomy is the removal of the entire breast, while lumpectomy removes only the cancer and surrounding tissue. Survival for mastectomy or lumpectomy with radiation appear to be about the same, but lumpectomy is only

recommended instead of mastectomy if it is followed by radiation (Health Canada, 1999). Systemic treatment is meant to kill cancer cells that weren't removed in surgery, and halt disease progression from metastasis elsewhere in the body (Benjamin et al, 1998). Early stage breast cancer may require only local treatment.

Lymph node dissection is done at the time of surgery. The number of nodes with cancer cells is an indication of the extent to which the cancer may have spread. Having negative nodes is a very good sign, between 60 and 70 percent of these patients will not experience a recurrence after primary therapy with surgery or surgery and radiation. However, breast cancer still recurs in about one third of these node negative patients, which is why chemotherapy is recommended. There is no way for doctors to predict which of their node negative patients will fall in that one third. This necessitates a careful examination, by the patient, of the potential benefits and risks of treatment. Lymph node dissection can have lasting side effects as well. Removal of lymph nodes means there are fewer lymph nodes to drain the tissue from the arm, and the fluid can collect, leading to painful swelling, called lymphedema. Exercise and avoiding strenuous activity are recommended to prevent lymphedema (Health Canada, 1999; Love, 1995).

Treatment after surgery is called adjuvant treatment. These treatments include radiation, chemotherapy, and hormonal therapy. Radiation improves chances of survival by killing remaining cancer cells at the site of the primary cancer. Radiation can cause discomfort from burned skin, tiredness, throat problems, and a small chance of developing esophageal cancer. The skin exposed to radiation may also change in texture, discolour, and cause discomfort in the first five years following treatment (Health Canada, 1999; Love, 1995).

Chemotherapy is used as an adjuvant therapy when no clear evidence of cancer can be found but certain factors, such as a tumour that is larger than 1cm, and/or is invasive, and/or positive lymph nodes, indicate an increased risk of cancer recurrence. Chemotherapy means literally, treatment with chemicals. It uses cytotoxic drugs to kill all the rapidly dividing cells in a person's body, including any cancer cells that have spread from the primary tumour throughout the body by way of the lymphatic system of the blood stream (Love, 1995; Nuland, 1997).

Chemotherapy drugs are delivered in combination to achieve the maximum effectiveness in killing tumour cells, but without making them resistant to the chemotherapy. Chemotherapy is the most effective systemic treatment for pre-menopausal women with ER negative cancers (Health Canada, 1999). Studies show that when chemotherapy is given to pre-menopausal women with positive lymph nodes at the time of diagnosis, overall survival rates are improved by 10%. This means that "about one fifth to one third of the women who would have had recurrences in the first 10 years after diagnosis will live beyond 10 years" (Love,1995:32).

Standard chemotherapy can increase risk of lung and heart disease, as well as leukaemia and liver disorders, and can cause a variety of side effects. Side effects vary in severity according to the individual and the drugs used, but the majority of patients experience at least some side effects. Nausea is common, and the severity depends on the drugs used. Up to 88% of breast cancer patients receiving chemotherapy experience nausea (Spiegel, 1997). Most women also lose their hair. Pre-menopausal women who receive chemotherapy may be put into early menopause, the side effects of which can be more severe than natural menopause, and which also causes infertility. In addition,

chemotherapy lowers counts of white and red blood cells and platelets (which help blood clot), lowers immunity, and can cause mouth sores (Health Canada, 1999; Ganz, 1996; Love, 1995, Rosenthal, 1997).

Chemotherapy is also limited by the dose that patients can tolerate. There has been a move in the treatment of breast cancer towards more aggressive chemotherapy, given in fewer sessions of treatment. This is founded on a belief in dose response in chemotherapy. Some researchers believe that there is evidence that higher doses given early in the treatment of the disease will kill more cancer cells, and result in more durable remissions (Tannock, 1998). High dosage chemotherapy (HDC) is an aggressive treatment; one that is so toxic it completely destroys a person's white blood cells, and is followed immediately by bone marrow transplant. For a very small percentage, this treatment actually causes death, and can cause long-term health problems in others. It is as yet unknown whether HDC is effective, or if it is more effective than standard doses of chemotherapy. Those receiving HDC in Canada and the United States are generally involved in a clinical trial.

If tumour cells are estrogen or progesterone receptor positive, then modifying a woman's hormonal environment with drugs, or sometimes the removal of ovaries, can provide an effective treatment by preventing the growth of the tumour. Tamoxifen is a hormonal treatment that has received a lot of attention from the media recently, both as a treatment for breast cancer, and a preventative for those who are at high risk to develop breast cancer (Tannock, 1998). Tamoxifen blocks hormones so that they are unable to stimulate tumour growth. Hormonal treatment does not reduce the number of cancer cells in the body, but prevents cancer growth. It does pose a small risk, by slightly

increasing a woman's chance of uterine cancer. Side effects include hot flashes. Hormonal treatment is recommended for post-menopausal women who are ER positive (Health Canada, 1999).

After treatment, a breast cancer survivor must maintain a follow-up regimen. A breast cancer diagnosis necessitates careful monitoring for the rest of a woman's life, as she will always be more vulnerable to dying of breast cancer than those who have never had the disease (Love, 1995).

### Psychosocial aspects of breast cancer

The psychosocial literature on breast cancer looks at issues that centre around adjustment at different stages of the disease trajectory. This literature has grown in recent years. Researchers in nursing and social science have developed research to investigate how breast cancer affects four different aspects of a woman's well being; physical, psychological, social and spiritual (Ferrans, 1994; Ferrell, 1997, 1998). Breast cancer poses issues of adjustment in each of these domains as they go through diagnosis, treatment, long term survival and/or recurrence. Psychosocial research is a useful framework for some of women's experiences with breast cancer, although in narrative accounts these domains are not so clearly separated, or mutually exclusive.

### *Making Choices*

Having an understanding of their disease is important for women with breast cancer, as is being involved in decisions about how it will be treated. In a recent study of quality of life issues in the first year after breast cancer diagnosis, it was found that there is no significant relationship between psychological disturbance and the type of breast cancer surgery, or choice of adjuvant therapy (Ganz et al., 1999). Other research also shows this, and that patient participation in decision making is more important than the type of treatment (Cimprich, 1999; Spiegel, 1997).

There may be a difference, however, in how medicine presents options, and how patients understand them. A Canadian study of decision making among women with early stage breast cancer, explored the related issues of women's perception of treatment options, their understanding of treatment benefits and risks, and the role they wanted for themselves and their oncologists in treatment decision-making (Charles et al., 1998). Women were presented with different options that were explained to them, but the researchers found that these women did not perceive a real choice.

From the oncologist's perspective, presenting information about these two options (whether or not to have chemotherapy) allowed the patient to evaluate the risks and benefits of treatment versus no treatment and to make an informed choice. But, from the patient's perspective, these two options were not perceived as of equal value. A choice could be made only when there were meaningful treatment options to choose from. When the options presented were limited to 'doing something' versus 'doing nothing', most women did not perceive this as a meaningful choice; rather, they felt that their illness gave them no choice but to undergo treatment (1998: 77).

Doing everything possible was an imperative for women in this sample, regardless of the predicted efficacy of the treatment. In the interviews they tended to emphasise the potential positive effects of treatment, even if the statistical chance was

small. As one respondent said, "you realise that the percentages are only maybe three or four per cent... *I could be that three or four per cent*" (1998: 80, italics in original).

The authors speculate that an emphasis on positive attitude and positive thinking leads women to interpret statistics in an overly optimistic light. "Interventionist as opposed to watchful waiting strategies provided women in our study with a sense of control over a disease which they saw as dangerous, frightening, unexpected, invasive, mysterious, and having the potential to spread rapidly throughout their bodies" (1998: 86).

For women with breast cancer, many important exchanges with physicians and other health care professionals take place in a clinical context. These doctor patient interactions influence how a woman understands her illness. To truly benefit the patient, however, the physician must also acknowledge their interpretative role, "to allow the meaning of the illness to arise within the triangular interaction of the patient, the physician, and the patient's story of illness" (King and Stanford, 1992:195).

### *Diagnosis and Treatment*

Research has established that the most anxiety-provoking phase of breast cancer is immediately after diagnosis. One study found that 83% of women treated for breast cancer found the pretreatment period more stressful than the period after surgery (Northouse, 1989). The reasons for this included a high level of uncertainty, the need to make overwhelming treatment decisions with minimal guidance, and scheduling problems that delay surgery. In a study of pre-treatment distress, Cimprich (1999) found

that women reported higher levels of distress after diagnosis but before treatment, manifested by insomnia, fatigue, loss of concentration, and cognitive distress.

The physical effects of cancer treatment pose major challenges as well. In addition to the side effects of treatment, the effects of early menopause as a result of chemotherapy can cause problems such as hot flashes, sleep disturbance, vaginal dryness, and emotional lability, as well as infertility. Weight gain and lymphedema are also problems that persist years after treatment (Carter, 1997).

How a woman copes with breast cancer influences her psychosocial adaptation to breast cancer, and is the concern of many psychological studies. "Coping styles are related to adjustment and, in some studies, survival time" (Spiegel, 1997: S1-36). It has been found that denial and passivity are the least effective modes of coping, while confrontational, active modes are better. One study (Carver et al., 1993) found that acceptance was the prevalent means of coping, significantly higher than coping through disengagement. "These findings reflect the fact that the women of this sample generally retained an orientation that kept them engaged with their lives, rather than giving up" (1993: 379).

Hack et al., (1994) in a Canadian study examined patient preferences for diagnostic, prognostic, and treatment related information. Using interviews with women with stage I and II breast cancer, the authors explored the kind of information patients wanted to have to satisfy the degree of involvement in treatment decision-making they desired. A significant relationship was found between patient preferences for involvement in treatment decision-making and preferences for illness-and treatment-related information. Another study (Cameron, 1998) examined these issues for women

over 60. It was found that women of this age are less likely to seek information about their disease (1998: 44). As in other research (Silliman et al., 1998) it was found that older women with breast cancer do not question their doctors, rely heavily on their doctors for information, and tend to be passive participants in decision making about treatment.

Psychological stress usually levels off one year after diagnosis, and after the completion of active treatment (Ashing-Giwa, 1999; Ganz, 1998). Less than 10% of women significantly worsen during the first year after diagnosis (Ganz et al, 1996). A significant percentage of women continue to experience physical, emotional and psychological problems beyond the first year however, particularly sexual problems.

There are substantial differences among individuals and looking at illness stages, as opposed to time away from diagnosis, only serves to highlight the fact that coping with breast cancer is a process that fluctuates and changes according to the immediate circumstances of an individual's illness (Cimprich, 1999; Heim, 1997). In a qualitative study, Carter (1993) discovered that breast cancer survival is not experienced as linear phases, and even well after diagnosis and treatment survivors may experience periods of loss, or times when they are more aware of their survivor status and the impact on their life.

### *Body Image*

Body image, and its impact on a breast cancer survivor's well being has been the subject of much research (Ganz, 1999; Lanellier, 1998; Neill, 1998). Breast surgery

poses body image problems, as does hair loss from chemotherapy. Weight gain, swelling and skin discolouration are also common problems resulting from cancer treatment.

Women who have a breast or both breasts removed because of breast cancer may opt for different types of reconstruction, which include saline implants, or reconstruction using abdominal tissue (called tram flap reconstruction). Or they may decide against reconstruction and decide to wear a prosthesis, or nothing at all (Langellier, 1998; Neill, 1998).

Women differ on the issue of whether to wear a prosthesis or elect for a type of reconstructive surgery, or neither. In a qualitative analysis of women who chose to have reconstruction after mastectomy, Neill found that the most salient theme among those interviewed was, "getting my life back" (1998: 746). Neill found within her sample that wearing a prosthesis was seen as an impediment to getting back to normal life. These women felt that having a reconstructed breast would help them to feel normal again, and bring them as close as possible to their pre-diagnosis self. "Breast reconstruction, in the view of these women, offered the best opportunity for avoiding the appearance of being maimed, and for retaining a positive, integrated sense of self" (1998: 749).

In contrast, Langellier (1998) found that some women she interviewed were indifferent to the loss of their breast, and opted not to have reconstruction as they were comfortable with their body without it, or they elected to wear a prosthesis. These women did not consider reconstruction central to coping with their breast cancer experience, or living a normal life afterwards.

For many women with breast cancer, the hair loss that results from chemotherapy has the most devastating effect on their self-image. Alopecia has been cited as the reason

that some women consider refusing chemotherapy treatment, or even actually refuse it (Williams et al., 1999). Hair loss is a more visible reminder of the disease, and can affect body image, self-esteem, and social interaction. Women interviewed by Williams et al. were aware that they would lose their hair, but were not prepared for it to come out all at once. "All of a sudden, you go into that shower, and you start to wash your hair, and then you come out and you have no hair, and the hair is all over the shower, the tub, the walls, your hands and body. That was the most traumatic thing in the world" (in Williams et al., 1999: 1465).

### *Survival*

There is no cure point for breast cancer survivors, only an on going survival process. Because the statistics show that more women are both being diagnosed with breast cancer and surviving it, breast cancer survival has been conceptualized as a distinct research area. For many women diagnosed with breast cancer it is a life-altering event, with lasting impact on their lifestyle, relationships, expectations of the future and overall well being. "It was like the diagnosis was the turning point in my life... Everything revolved around it... it guided everything I did and still do" (in Pelusi, 1997: 1349).

In addition to worry about recurrence, there are other long-term effects of breast cancer on women's lives. For example, premature menopause leads to infertility, an issue that may be downplayed at the time of diagnosis. "It was hard because I never had children, I didn't realize that I wouldn't be able to have children... you're just trying to save your life. So you go through the treatment but after you're done, those things start to matter" (quoted in Ferrell, 1997: 405).

Ferrell (1997, 1998) found that women coped with survival by adjusting their sense of the future, and balancing hope and reality. Survivors have a heightened awareness of their own mortality, and though they continue to hope for a long life, they are conscious of the possibility of recurrence. It is not unusual to feel lost at the end of treatment, like they have lost the safety of actively working to prevent illness (Clarke, 1985). Any new symptoms are extremely anxiety provoking, as are check-ups. After treatment they may feel that even the stress of everyday life might bring on a recurrence; "I do have a stressful, full life which I sometimes wonder if I might give myself cancer again. Or I'll get it again because of the stress, because I know what it does to the immune system" (quoted in Ferrell, 1998: 7). Ferrans (1994) found that some strategies that breast cancer survivors use to cope with uncertainty and exercise control include seeking information, self-education, diet and spirituality.

To assess how much treatment women would withstand for what degree of benefit researchers posed four different hypothetical clinical scenarios to women diagnosed with stage I-IIIa breast cancer (Charles et al., 1998). The women interviewed were given four treatment alternatives for a woman with metastatic breast cancer and a life expectancy of 18 months. Side effects of the treatment options were systematically varied from low (hormonal therapy) to life threatening (high-dose experimental chemotherapy) and were consistent with common clinical situations. Women were asked if they would elect to receive each of these treatments if it had a 50% chance of extending life expectancy for 5 years, 18 months, 1 year, 6 months, 1 month, or 1 week (1998: 860). The researchers found that the 6 month point was where subjects shifted their preferences in treatment.

It was found that a small but substantial percentage would risk very high toxicity for a very small prolongation of survival, and more than half of the subjects would select chemotherapy without physical symptoms. The authors conclude that in light of a recurrence, these women feel that doing something, if only for peace of mind, is better than doing nothing. "This underscores the complexity of the quality-of-life construct in which patients may be temporarily trading off one aspect of quality of life (physical well-being) for another (emotional well-being)" (1998: 864).

If a woman does experience a recurrence, studies show that she will likely experience more distress than with her first diagnosis. In a study of recurrent breast cancer, one study found that overall quality of life, general health, emotional distress, social distress, and physical symptoms all worsened after a recurrence. Women showed significant improvements at follow up six months later, but on all measures except social distress, the quality of life ratings continued to be poorer than they had prior to recurrence (Bull et al, 1999). With a recurrence women may perceive a greater threat of death, find decisions harder, have more sexual problems and greater fear of pain (Northouse, 1995).

Qualitative research on survivorship has looked at the meaning of breast cancer in women's lives, and found that it is not necessarily all negative. In one study, 95% of respondents reported that they thought their treatment had been worth while (Ferrans, 1994: 1648). Further, many reported benefits from their cancer experience, including the development of better health habits. A number also reported making positive life changes, including re-prioritizing their life according to their own needs.

### *Social Support*

Although the needs and experiences of women with breast cancer are diverse, social support can be defined generally as involving one or more of a) emotional concern, b) instrumental aid, c) information, and d) appraisal (McLean, 1995). This support can come from a partner or spouse, children or other family members, friends, co-workers, professional caregivers, support groups or any other social or community ties. Findings suggest that social support for women with breast cancer can increase their chances of long-term survival, or increase their survival time (Spiegel et al, 1989; Waxler-Morrison, 1991), although later studies found no conclusive relationship between psychosocial support and survival time (Gellert et al., 1993). It has been shown that social support results in fewer adjustment problems (Northouse 1988).

Barriers to social support include the stigma that cancer still has, and the tendency some people will have to avoid someone who could die. Women with breast cancer often speak of finding out who their friends really are (Lugton, 1997). Peters-Golden (1982) found that only half of the breast cancer patients studied assessed the support they received as adequate to fill their needs. However, research has found that women with breast cancer report high levels of support, indicating changes, possibly due to a higher public awareness (Zemore and Shepel, 1989).

Breast cancer affects not only individuals, but their families. A number of studies have examined how families cope with a diagnosis of breast cancer (Hilton, 1996; Lewis, 1993; Pistrang, 1997). Hilton (1996) found that normalization is a primary family strategy. In this qualitative study, "being normal," "getting back to normal," and "doing normal things" emerged as an important theme. Strategies for getting back to normal

included seeing the family as normal although coping with a different situation; maintaining or returning to usual patterns; minimizing disruption; re-framing the situation; and putting cancer behind them (1996: 607).

Maintaining the usual family routine was considered a sign of health, although this could put subtle demands on women with breast cancer to return to their normal roles before they are able. "The routine is what makes me secure... the moment the routine changes, I have a harder time dealing with any kind of problem and that was the hardest thing.... *If you can do the routine as you always did, then things can't be that bad*" (in Hilton, 608 emphasis mine). In efforts to normalize, families also try to minimize time spent on illness, to maintain individual roles and functions within family, and work together to minimize disruption. One risk of normalizing is that women will be reluctant to ask for help with everyday tasks (Hilton, 1996).

Lewis (1993) found that couples vary in the extent to which they acknowledge breast cancer in daily life. For some the cancer was a looming, unspoken presence, and for others it was the subject of every conversation, woven into all aspects of everyday life. Some couples coped by trying to balance time spent talking and dealing with disease with time spent doing other things together. Breast cancer can also create tension between a woman and her partner in regard to their physical relationship, what one woman's husband referred to as the problem of "what you think I think about you..." (Langellier, 1998).

Waxler-Morrison (1991) suggests that friendships are generally less ambivalent, more controllable and concretely useful relationships as compared to the more complex relationships with family members.

It is possible to encourage friends who provide something useful and to discourage friends who do not; such choice is usually not possible among family or relatives. Further, friendship relationships are usually less encumbered with past and future obligations than are family ties (1991: 181).

Women with breast cancer need support in facing uncertainty and mortality, but they may choose not to share these fears with those closest to them. Other survivors can be a valuable source of support in acknowledging the reality of the situation. As one woman said of her support group, "It's not a case of "I've got cancer, I'm very ill." Everybody is very ill. You're no worse or better than anybody else" (in Lugton, 1997: 1189). Peer support helps women to identify with others in their situation, and see examples of the wide variety of experiences. The women in Lugton's sample said that those who recover are useful examples, but women with far more serious illnesses can also help women to realize that their situation is manageable. "Black humour" also helps to normalize. Those with cancer can share funny moments in their illness and help each other to laugh at the situation (Lugton, 1997).

Although it is not clear why peer support helps breast cancer patients, or if it helps different people in different ways, it is accepted that it does benefit the majority of those who take part in some type of group support (Samarel et al, 1998). In one study, three quarters of women who were surveyed expressed a positive change in attitude towards their breast cancer, and all regarded participation in the group as positive (Samarel et al, 1998). Support helps women know what to expect, to set their own priorities and accept limitations. It encourages hope, and helps them to know they aren't alone.

## *Conclusion*

Cultural, medical and psychosocial perspectives all appear in the narratives to follow. Many of the themes in the psychosocial literature appear in the breast cancer list narratives I explore in the rest of this thesis. The psychosocial research focus is on adjustment; what about breast cancer most affects women, and how women cope at different stages of their illness, and thus contributes a lot to our knowledge of living with breast cancer. It often addresses different aspects of the illness in isolation, however, and that is where a narrative approach has the potential to make a contribution. By looking at the stories women tell about their illness it is possible to gain some insight into how breast cancer is experienced by them.

An understanding of the physiological realities faced by these women is important to a sociological discussion. Previous work on narrative and illness experience does not necessarily address the medical context of women's understanding of their illness and treatment decisions, or the importance of medical research and terminology to how they tell their stories. Finally, the cultural realm frames these narratives, and the media in particular shapes the public's understanding of the relationship between cancer and lifestyle, emphasizing choice and control.

## Chapter Three

### Treatment Decisions

#### **"Statistics and Personal Values"**

Although I am definitely not the most analytical person in the world, I spend a good deal of my time each day combing through the detail of large computer databases and processes. One thing that always happens to me, though, is that eventually there will either not be enough data to absolutely identify the root cause of whatever I am studying, or there will not be enough time to study longer. And at that point I say to myself, "what is the right thing to do, today, with the information I have?" And that is what I have to do, for myself and my company. And that's what I did for myself and for my family. Aggressive induction chemo, ABMT (autologous bone marrow transplant), and radiation, and now I am three years out, when I wasn't sure I'd live to see my little one go to kindergarten (Theresa).

When women first come to the breast cancer list, it is often because they want information, and friendly support. One of the most difficult aspects of this disease is making decisions about treatment. A woman diagnosed with breast cancer is immediately confronted with these decisions, at a time when she is vulnerable and may lack knowledge about the disease and her situation (Cimprich, 1999). Those who look for clear answers about what they should do find that the research to date doesn't always provide these. Instead there are statistics, and a variety of opinions (Love, 1995).

During my time on the breast cancer list I found that one of its main uses is for those posting to solicit opinions about treatment and sound out their dilemmas about what choices to make from the available options. During my research period I found these discussions centred on post surgery treatment, particularly chemotherapy, as well as radiation and tamoxifen. The reason for this may be that almost invariably breast cancer requires some type of surgery, whether mastectomy or lumpectomy. It could also be that

these women only come to the list, or post to the list, after their surgery. While these posts aren't all complete narratives, they contain elements of narrative, and offer insight into these treatment decisions.

This message is one I have been longing to share with all of you. Basically it is one of appreciation for all of the love and support shown here for one another. I'm feeling negligent (and ready to make amends!) for while I was struggling with my own diagnosis, consults, tests, and pending treatment I have been unable to look outwards and be supportive of others needing it as much as I. I first signed on to this list in November, shortly after diagnosis.... I was on information overload-knowing that I have cancer but not knowing much more than that. I think that I could have easily just stuck my head in the sand -- if it had not been for the discussions, and posed queries, and posted research. I had to keep reading it!

In the first chapter I presented illness narrative as a way of gaining insight into illness experience, particularly experience that is not made explicit, or is overshadowed by a biomedical perspective on the body and disease that isolates disease from the rest of an individual's situation and life experience. This chapter will examine different breast cancer list members' views on their treatment; how they perceive treatment and its impact on their body and their disease, how they characterize their treatment and illness, and how they made decisions about available treatment based on their personal values. This chapter is not a medical discussion. Rather, my intent is to illustrate a striking aspect of these accounts of post surgery cancer treatment: that personal context and meaning are invariably present in these narratives.

Because outcomes are always uncertain in breast cancer treatment, decision making is a weighty responsibility to be faced with. No one wants to risk making the wrong decision, so women must feel as though it was the right thing to do at the time and in their circumstances, whatever the outcome (Charles et al., 1998). In posts to the breast

cancer list about post surgery treatment I found that three different perspectives emerged. Living as normally as possible, for as long as possible is the goal for everyone. This may mean a) using chemotherapy and other treatments to try to prevent recurrence or lengthen life; b) refusing treatment if it compromises quality of life for too little return; or c) for those with advanced breast cancer, using treatment only for the alleviation of symptoms.

The breast cancer list promotes information seeking as a strategy for dealing with breast cancer and choosing treatments. It is evident in the posts to the list that many of the women who are active there do their own research, reading, and searching on the Internet. As a result, they develop a sophisticated knowledge of the complexities of breast cancer, and the treatments available. A high level of awareness is presented on the list, particularly in replies to newcomers, as the best basis for decision making. However, *awareness* can be thought of as more than just knowledge about the disease. It also includes knowledge of one's self and one's own needs and priorities.

Women on the list have commented that the value of the list is that it can provide information on all sides of an issue. For example, if one list member posts that she feels good about having done adjuvant chemotherapy, another will post her reasons for deciding not to do it, and someone else will likely say that she did it, but has regrets. When a person first approaches the breast cancer list with questions about treatment, she will typically receive a variety of views and personal experiences from those who respond.

In following these women's accounts on the breast cancer list it is clear that their decisions are influenced by a combination of external factors and personal values. External factors include the treatment philosophies of physicians, the availability and

quality of treatment protocols, medical authority, and the amount of knowledge that is available and accessible to the patient. Treatment decisions require a person to look at her body in unfamiliar ways; physical and mental energy, comfort, and survival all factor into the decision, where before breast cancer, these things were likely taken for granted. The rational consideration of treatment options like chemotherapy means weighing the hoped for outcome against the known risks and side effects. As Theresa's quote at the beginning of this chapter illustrates, the most rational decision about breast cancer treatment will still be subjective.

Although the list promotes active patient participation and supports a range of choices, from alternative to aggressive and experimental treatments, participants also defend their personal choices. Once a decision is made, a woman needs to believe that it was the right one for her. This process of decision making and validation results in different characterizations of treatment, and depending on their perspective, individuals will look upon treatments differently.

## Fighting Hard against Cancer

Lay interpretation of biomedicine rests on the cultural understanding that medicine is the intervention that will cure a physical ailment, and particularly on cultural metaphors such as *fight* and *battle*. Cancer is a war to be fought by the patient, against the invader in her body, with the help of medicine. As Susan Sontag notes in *Illness as Metaphor*, this interpretation has been institutionalised by the medical profession.

The military metaphor in medicine first came into wide use in the 1880s, with the identification of bacteria as agents of disease. Bacteria were said to "invade" or "infiltrate." But talk of siege and war to describe disease now has, with cancer, a striking literalness and authority. Not only is the clinical course of the disease and its medical treatment thus described, but the disease itself is conceived as the enemy on which society wages war (1978: 66).

Chemotherapy plays into this cultural interpretation very well. Chemotherapy is an effective treatment, for many, for the prevention of a cancer recurrence, or to achieve a remission, but it has serious side effects. Cancer patients may therefore regard it as a difficult regimen that signifies a hard fight against the disease, and draw a connection between the toxicity of chemotherapy and their desire to "fight hard" to regain health. This was evident in Kelly's narrative.

I have made my decision today. I went with my gut, my reading, and my discussions with this group. I saw the Oncologist today, finding out the survivability "odds" were just over 50%. Very close, in my limited cancer education, to what I suspected. I start chemo (AC) tomorrow. Then radiation, then tamoxifen. What he said jived with what I already knew and with what I could understand. Knowing that he is good as an oncologist (I know some people he has pulled through, he comes highly recommended) helped me make my decision too. Plus, I want to get started on this fight. NOW.... I am a tired fighter- I have fought too many medical conditions up to this point of breast cancer. And so I have decided to let the fighter rest for a bit, and to let the toxins do the fighting for me, for a while. I know I will get sick as a dog, but I am ready to do this (Kelly).

Some women on the list who have had chemotherapy have commented that they never would have thought it was something they would be able to do. In the end, however, their evaluation of the risks versus the rewards makes it the only decision possible for them, as all the information they have indicates to them that this may be the thing that keeps them alive, by keeping the cancer away forever. Many of those who do chemotherapy do so hoping that they will never have to deal with either the cancer or the treatment again.

An "insurance policy" approach to treatment was evident in posts to the list. Women have indicated that they make decisions about their treatment by anticipating a

future recurrence, and then choosing the treatment that may prevent it. Chemotherapy and other adjuvant treatments are seen as an extra precaution against recurrence.

Chemo scares me, but so does not surviving. What a dilemma! So I am reframing my attitudes and thoughts. Chemo is my insurance policy- to help give me peace of mind. Not to be apprehensive would be abnormal. But I feel more like a survivor than a victim with these thoughts. Tamoxifen scares me, but so does not surviving. I haven't yet come up with a way to reframe that one. The stats are short of convincing (Toby).

Those who approach chemotherapy as "insurance" find peace of mind in knowing that they are doing something that could help prevent future cancer. It may also be tempting for a woman to believe that because she took the recommended treatment, she is safe from recurrence. Toby feels more in control of her health knowing that she is taking the treatments recommended to her.

Others have echoed this point of view, saying that they had to know that they did everything possible to survive. That way, if they do have a recurrence, they will have no regrets, nor will they feel that they could have prevented it. The possibility of over treatment, the side effects, and health risks are balanced by the chance that it may be the treatment which prevents a recurrence of their breast cancer. While Toby found the statistics on the effectiveness of tamoxifen to be "unconvincing", another individual might find tamoxifen more acceptable than chemotherapy. It is very much an individual perspective, based on an individual's acceptable level of risk and the degree of discomfort they are willing to accept for the anticipated return.

Women who choose treatments that result in side effects must find a way to deal with the physical and emotional effects they experience from them. One way to do this is to look upon the side effects as the cost of a possible cure or remission. As one list

member said about her bone marrow transplant, "I don't look back and I never blame the transplant for the pain and other problems. The cancer is the *thing* I blame." To this woman, the cancer is the disease and therefore the ultimate cause of all her symptoms.

The battle against breast cancer becomes fiercer when the future is threatened, as it is for those who have advanced stages of the disease and therefore less likelihood of recovery. In their narratives, cancer is the invader, and treatment is a bid to buy time. On the breast cancer list this is particularly common amongst those who play a strong role in the lives of others. For example, parents of young children see their future, at least in part, in terms of milestones in their children's lives. They want to be able to witness high school graduations, first dates, marriages, grandchildren; the unfolding of their children's lives, their experiences and their successes. Parents of young children feel it is very important to go through treatment, as their death and absence would have such an impact on their children's lives.

As a mother of 3 young kids, I feel it's my duty to do whatever it takes so I can be here to raise them; it's for their sake, not so much my own.... Even in 10 years, the youngest one would still be too young to grow up without a mother. How would my husband cope with the three girls? So, time, for me, is crucial" (Jody).

Jody wrote this post during a discussion of treatment options. Here she experiences her disease as a fight against time; time which she needs to raise her kids, that could be taken away from her if she refuses treatment. From this perspective, treatment becomes an imperative. It means that something is being done to prevent the shortening of one's life, and gives a woman the assurance in her own mind that she has done what she can to make herself well, for herself and for her family.

A feeling of urgency to do everything possible to cure the disease may prompt women to opt for aggressive, experimental treatment, such as high dose chemotherapy with stem cell transplant (HDC/SCT). Recent research indicates that higher doses may

result in a better response, but this treatment also compromises overall health more than regular chemotherapy.

Although women recognise HDC as a risk, they see it as one with great potential rewards. Again, the toxicity of the treatment is perceived as being related to its potential effectiveness as a cure. Women portray their decision to take this route as an all out, make it or break it attempt to get a remission and regain control over their life. As one woman on the list said, it is their chance "to blast the cancer out". For those who opt for this treatment, the time spent recovering is seen as compensation for the anticipated remission.

Annette chose to do HDC. After being diagnosed with metastasis, her perception of her disease changed, and she realised that her odds of survival were not what she had hoped for after her first diagnosis. She wrote to the list that she no longer expected a cure, as she did then, but in hopes of prolonging her life as long as possible she went for what she called the "mega treatment." Instead of considering maintenance chemotherapy, "I shook the dice and advanced to go."

Well yesterday I was given my "walking papers". I had done so well that it was time to be referred back to my oncologist. Most people would see this as a good sign, a positive sign. For me though, I am scared silly. Dr.-- scheduled an appointment for a CAT scan and chest Xray. Of course I knew that I had to have these done and I knew that I would have to go back to oncology. But that means facing my cancer again and I am not ready for that. Can you believe this? I had a stem cell transplant because of metastatic cancer and I now cannot face the cancer. What I did was play a game with my mind, saying that once I recovered from the SCR/HDC, that would be it. I was recovered and now I don't have to worry. Well, I knew that was not true, but that is what kept me sane for the past three months. Knowing that they would not be doing any scans or xrays, because nothing could be determined at that early point, so I could pretend that all was well. Now, I have no idea whether the HDC did its trick or not. I have no basis for my fear of the CAT scan. I just do not want to know either way. I want to pretend that it is gone forever. I really want to hide my head in the sand. But I cannot do that. So now I am scared! Because now I have to take out my cancer from where I had "placed" it. I had put it in an imaginary box up on my shelf. I had wrapped it tightly in twine and I had shoved it way back. Now I have to go get it and I do not want to.

HDC allowed Annette to stop dealing with her cancer on a daily basis for awhile, and stop worrying about all the "what ifs". Now she has to acknowledge her disease once again, and think about what she will do if the HDC has not "done its trick". For her, intensive treatment created a sense of refuge from her cancer. This also brings up an issue that I will discuss in the next chapter, that the aftermath of treatment can be difficult as well, because women just have to watch and wait. Treatment is an active way of dealing with the cancer, and for that reason it may feel like a refuge (Clarke, 1985; Ferrans, 1994).

Faced with the uncertainty posed by a diagnosis of breast cancer, some women will focus on the present and obscure the future, while others will fix their attention on hoped for outcomes. Those who refuse to do adjuvant chemotherapy regard it as too great a threat to their quality of life now, while those who proceed with it focus on the impact it could have on their chance of recurrence, and how it can protect them. From their perspective, spending several months very ill in order to know that they fought the cancer as hard as they could is the bargain they choose in hopes for a cure.

Chemotherapy, radiation, and other treatments also provide a needed sense of security for some women that comes from knowing that *something* is being done (Charles et al., 1998). For them, to forego further treatments would mean giving up whatever chance of remission they might offer. When this need to do something is part of the decision making process, then treatments aren't simply looked at in terms of their own merits, but in a "what have I got to lose" sense- as something that is available that may help. In the face of cancer, women will make decisions based not only on their knowledge, but their hopes, fears, and anticipation of the future.

## Treatment as Illness

Treatment is something that can be endured provided that there are substantial good days, or even good parts of days. Hormonal treatment may cause uncomfortable side effects, and chemotherapy may result in lost time, sickness, and an overall feeling of exhaustion. But in spite of this, for many there are still pockets of enjoyable normal life, and very good reasons to endure the side effects. Sometimes, however, treatment will be so devastating that patients cannot tolerate it, and they reach a point where they feel they have done as much as they can do and wish to try something else, or nothing else. For these women treatment merely contributes to their feeling of illness with no perceived benefits.

Women who know they have breast cancer do not always feel sick. Often it is treatment that causes feelings of sickness. Diagnosis is not likely to have been preceded by any illness symptoms unless the cancer is very advanced. The illness experience is generally defined by the treatment, and the discomfort caused by side effects, rather than symptoms of the breast cancer itself (Love, 1995; Frank, 1993). This adds to the feelings of disbelief that a woman may experience in the face of her illness; knowing that she has cancer, that she must turn her whole life upside down getting treatment, worrying about the future, but yet not even feeling sick.

It is just hard to cope with in the sense that I was not ill. I just wake up and there is THE LUMP and my whole world is upside down ever since. I feel like where is my life? Did someone slip in when I was not looking and steal it out from under me or something? (Jean)

From a medical perspective the purpose of treatment is to cure the cancer, so literature written for women with breast cancer will tend to portray the illness caused by

treatment as minimal, manageable, and above all, necessary (Rosenthal, 1997). The real illness, from the medical standpoint, is the cancer. Women with breast cancer may become resentful of this inference. In a rational presentation of the pros and cons of chemotherapy, complaints about nausea, tiredness and other symptoms may be made to seem minor. As one woman said about the flu-like symptoms caused by chemotherapy, "they tell us that like it is nothing, but when in your life do you feel worse than when you have the flu?" Fiona wrote to the breast cancer list about the management of her symptoms while on chemotherapy,

While drugs worked for me in keeping nausea completely at bay, that does not mean that my digestion seemed normal. I felt like I had a permanent case of queasy indigestion. In the regimen I followed... about the time I was beginning to think I was somewhere near all right it was time to start over again. I tried to walk to the store regularly, but it would take the better part of a week after treatment before I was up to it, then a few more days before I'd be willing to try again, then I'd get sick or something.... the exhaustion for me was cumulative.... It really took a year to recover from the exhaustion of chemo. In a way I feel that I pretty much lost most of a year to chemo (Fiona).

Chemotherapy affects people differently, but for many it creates an exhausting cycle. Typically, each successive treatment is a little harder and requires more recovery time. By the time a woman begins to recover and feel more like herself, it is time for the next round (Love, 1995; Mayer, 1997). Lost time is a common theme on the list when discussing reasons for refusing treatment or discontinuing treatment. These women feel they cannot see a time beyond chemotherapy, and in the meantime their whole life is swallowed up with the side effects from treatment. This may prompt a decision that they would rather have quality of life now, than live a seemingly never-ending life of sickness from chemotherapy.

Because chemotherapy is a treatment, people may not be truly prepared for how sick they are going to feel. Sheila wrote to the list after her first chemotherapy treatment,

and talked about her fear, discomfort, and the unexpected physical sensations she felt.

The subject line of this message was, "they lied".

Yesterday I had my first CA (chemotherapy) treatment. All went fine, the nurses just kept reiterating to take my anti-nausea pills twenty-four hours after the treatment... What they didn't tell me was that I wouldn't sleep last night cause I could feel the poisoning drugs pulse through my body. My skin felt stretched to its limit. My bones and joints ached, I felt as if I could feel every sinew in my body. My temperature went to 100.7. I drank 2 gallons of water and peed red all night hoping that at least some of the drug would stay around to kill the cancer. Couldn't find a comfortable position. Finally went to sleep at 4am. I feel better now, only my head hurts and I fear 3pm when the nausea should start. I am so angry that I have this disease, I am so angry that I feel like a sick person I am so angry that the drugs to help us cost so effin' much. I am so angry that all the doctors and nurses I saw yesterday never had to go through with this, so they had no idea that I thought I would die in the night. (Sheila)

Sheila evidently perceived a lack of understanding and empathy about the experience of chemotherapy on the part of the medical profession. She later said that she regrets her decision, that had she truly realised how chemotherapy would make her feel, she probably would have taken her chances with just surgery.

A woman may re-evaluate her stance based on her experience with treatment, even though the risk of recurrence remains the same. Members of the list who decide not to do chemotherapy may already know from a previous experience that they cannot tolerate it, and it is not something they wish to do again, or they may find that the risks of chemotherapy are not outweighed by its benefits. These women will often look for something else, perhaps doing hormonal treatment only, or alternatives such as herbal medicine or a macrobiotic diet. Those who decide upon diagnosis not to do chemotherapy may also look for less intrusive treatment that will fight the cancer without compromising their overall health and well being.

I could not do chemo at all because inside me it was not the way I needed to go. I could not do radiation either. It was the toughest decision I have ever made to say NO and deal with the pressure of my doubting self and the oncologist and nurses to say YES. I knew so deeply inside though. I put off my appointments, I refused to return calls, I did everything to sabotage the final decision needed on the radiation and chemo. I used another product from the alternative field of things

and I do not regret it to this day. I do though often think of the power my inside self had to make the rational mind listen to her. I am a much, much stronger person since that day and I suppose if I get mets (metastatic breast cancer) someday I may well think I should of, might of, ought to have, etc. but it will be for a short thought. I also am not going to cry over spilled milk too long as it really takes my strength away and I do not move forward (Phyllis).

Women on the list who discussed opting not to do chemotherapy or radiation because of their side effects talked about being aware of their body and well being, and portrayed some treatments as simply too great a threat to the integrity of their body and self. As in Phyllis' case, these decisions are made based on intuition, or "gut instinct", by listening to the body over the "rational mind". In Phyllis' narrative, the moment when she decided not to do chemotherapy was also the point at which she asserted control over decision making and defined her own needs.

Although Phyllis did seek treatment, from the "alternative field", it was one that she felt comfortable with, and which gave her an inner peace that chemotherapy could not. She used diet, and other alternatives to standard treatment to assist her immune system to kill cancer cells. Furthermore, she is determined not to second-guess her decision, even if she experiences a recurrence that may have been prevented by chemotherapy and radiation. This is a common theme in narratives about decision making. Women need to believe they did not overlook a reasonable option that may have helped them. The possibility of recurrence is hard enough to deal with, without feeling that failure to make the right decision will result in a later recurrence. Therefore, defending one's decision is critical. This means feeling that it is valid, and taking a staunch "no regrets" position. This is also true for those who *do* choose a therapy that compromises their quality of life, knowing that it may not help them, or that it may be

over treatment.

The impact of chemotherapy on the body is counterintuitive for some list members. Presented with chemotherapy as a treatment option when she was first diagnosed with breast cancer, Wendy found it a difficult decision to make, mostly because she could not reconcile herself to the anticipated side effects. "If chemo destroys your immune system why would I want to do that? It seems to the uneducated me that I would want my immune system to be working at its best." There is a tension implied here, between medical knowledge and personal experience. In the rational calculation of risk upon which medical decisions are made, chemotherapy makes sense. It may not make sense at all to women who have to deal with the time and energy lost to them during treatment and the feeling of sickness, and for whom the effects of the treatment generally appear as though they are health destroying rather than health promoting. Medicine may label this resistance as "denial" or "non-compliance" (Spiegel, 1997). However, those list members who discussed their decision to refuse standard treatment all still acknowledge the existence of their illness and use some alternative to treat it.

The posts by Phyllis and Wendy also suggest that perhaps these women are working from a different view of the relationship between their body and disease. Medicine promotes intervention as the best available standard treatment, as it has been subject to clinical trials (Love, 1995). This may be at the expense of alienating people from their own disease, by making them see the cancer as an enemy, and their body, the battleground. Those who choose alternatives may not be reacting only to the side effects of standard treatment, but also to the interpretation of cancer that it carries with it. They

may need to feel whole, rather than fragmented, and want to respond to disease by strengthening their body rather than weakening it.

Alternatives such as visualisation, vitamins, diet and other alternatives, all stem from the belief that by boosting the immune system, the body will fight off cancer without medical intervention. These alternatives are also frequently used in conjunction with medical treatment (Berliner and Salmon, 1980).

Colleen has written to the list many times about her decision to discontinue chemotherapy, and the validity of such a decision.

For those who know me, I think my position re further chemo is pretty well known. I am totally against it for myself now that I am living with metastatic breast cancer. I do not regret my first go at chemo. I disliked it intensely, but took each treatment as it came. I did "come up" for a breather by the third week, only to be put down again on day 21. For me, the effects were cumulative in nature ... Then the other shoe dropped, so to speak... I knew that with mets I was looking at a monster that I could only hope to keep at bay for a while...hopefully living with it as a chronic illness for a long while.

On the (chemotherapy) regime in 1995 I never came up for a breather. In my case, it was pure hell and nothing I care to go through again. But this is me. Some will do anything and everything to the end. (I respect any one's decision on whatever they do or don't do). For me, quality of life is more important. I don't have any illusions about the very end of my life. It will no doubt be miserable, but the suffering will have an end point, and then in my belief, a new beginning in another place. Personally, I cannot imagine living month after month, and for a few, year after year with maintenance chemo and all the side effects and debilitation. It is not that I do not have anything to live for and am giving up. I am young and have a happy and contented life. I happen to have a different perspective on chemo than many. My husband understands that the final call is mine, so I do not have to endure guilt trips re not doing everything in my power to stay alive regardless of how compromised my life is as a result of it.

(I) declined radiation.... I will use their radiation, etc. very sparingly and with great thought even in the future. I think spinal cord compression would get my attention. To think what lies ahead for me is frightening, so I try to keep my thoughts in today. Right now, I am sitting here and feel well. I will be grateful for that.... Please don't be swayed by my decisions. There are no guarantees with this disease.... I have said to my husband often that I believe someday

chemotherapy will go down in history as being totally barbaric and people will gasp at the thought. It is just not for me anymore.

Colleen is taking a hormonal treatment, and has a clear sense of when she would accept radiation, which she has refused for her bone metastasis. She also knows that for her, more chemotherapy will damage her time left, therefore considering it not worth while, even for a possible extension of her life. She says "quality of life is a huge issue" for her, and confirmed this in another post when she said, "I would prefer less time compared to chemo and its toxicity to my body... (even) if it can be proven that chemo extends ones life at stage IV. Some people do well with chemo and do not feel so sick, but my body (and mind) do not do well with it..." Colleen does not rule out treatment or dismiss chemotherapy altogether, but feels certain that for her, it is not worth while at this point. She also points out the doubt that always exists, concerning whether chemo does, for any one individual, extend life.

Those on the list who equate no treatment with quality of life may in fact pass up opportunities to improve longevity or alleviate cancer pain because they are determined not to be medicated or suffer the side effects of treatment. They evaluate quality of life in terms of the degree of medical management they have to undergo, because this interferes with living a "normal" life. In the quote above, Colleen refers to radiation treatment as "their" radiation, suggesting that she sees this treatment as something she has no investment in, or control over. She is judicious in deciding what would warrant radiation for her. The pain and debilitation would have to be beyond her control before she would see these treatments as necessary.

Colleen illustrates the development of a strong personal position that validates her decision. Not only has she refused recommended treatment, but she distances herself from the medical perspective, marking it as different from her own and incompatible with her personal agenda. Having accepted that the end of her life span will be shortened, she focuses on the present, what she wants now, and what will give her a normal life. Having

accepted that, however, she hopes to manage her disease as long as possible, as a "chronic illness", as long as that does not involve chemotherapy.

Colleen has often written about wanting to die in her own time, without drastic interventions that would extend her life at the expense of what, to her, is quality of life. "Quite honestly, I believe that stage IV will bring us all to the same destination eventually, but in different ways." This acceptance is key to the choices she makes. Because metastatic disease is incurable, Colleen feels entitled to choose minimal treatment that will preserve her quality of life right now, even if that means sacrificing the possibility of a longer life span.

After hearing an explanation of her prognosis, treatments and all the statistics, the prevailing message a woman will usually come away with is that adjuvant treatment provides an added advantage in fighting the disease, although for some that advantage is very small (Charles et al., 1998). Nevertheless, it is something that can be done, a way of coping actively with the disease. Medicine and oncology work to create options in chemotherapy, by refining treatment protocols. If the patient does not respond to one drug she can try another, and another, possibly working up to increasingly aggressive and experimental treatments. The decision to refuse treatment may become a difficult one to make, and one that needs to be defended to others.

On the breast cancer list there has been discussion of the option of not having more treatment, and how this decision could be justified in the eyes of others, particularly family members. Sue, a survivor who is currently disease-free explains,

As I have said before, I belong to the "less is more" contingent when it comes to what treatments I would choose if I were to have another recurrence.... X once wrote that those with advanced mets (metastasis) were like scouts, going on ahead and then leading the way for those behind. There are many "scouts" for those who choose to have chemotherapy, but not many to lead the way for those who choose to forego further treatment. So I don't really know what it would be like to let the disease progress without chemo.... I also think it would be difficult to resist pressure from friends and relatives and doctors to have more treatment. There is so much talk about "fighting" that I think saying no to chemotherapy

would be looked on by many people as giving up. I can just hear someone saying, "Sue refused chemo, and then it went to her liver and she died," or something similar. I don't think that's fair because many who *do* have chemo still end up with the cancer spreading, but if my husband, children, or siblings urged me to not "give up," it might be hard to stand firm. It might also be hard not to panic when the disease advanced and began to cause pain or great discomfort. It's so hard to know because I don't know anyone who has gone without treatment up till the end (Sue).

The connection made here between refusing treatment and giving up is a reflection of the cultural perception about cancer treatment, that aggressive treatment is always the best course of action. This may put pressure on terminal cancer patients to do anything possible to forestall their death. Sue doesn't think it's fair that her family and friends would expect her to accept treatment regardless of whether it helps or how it makes her feel. She perceives a lack of understanding about the extent to which she and her doctors can control the disease. She notes also the lack of leadership, support and guidance for those who take this route.

As with those who decide in favour of various treatments, Sue has come to her position by looking into the future and imagining how she would feel after making a choice like this. She is also imagining how others would react and how that might affect her.

## **Palliative Treatment**

Palliative treatments involve the judicious use of treatment options like chemotherapy or radiation for pain relief and prolonging life in advanced stages of cancer. The palliative use of chemotherapy and other treatments is meant to control symptoms, and is generally not expected to produce a cure. Unlike adjuvant therapy for newly diagnosed cancer, palliative treatment does not involve projecting into the future and balancing possible outcomes with comfort. Treatment at this stage is meant to

improve the breast cancer patient's current situation. In discussions of chemotherapy in particular, and its impact on quality of life, list members have spoken up to remind others that for some, treatment is what allows them to remain functional, and thus improves their quality of life. Romanticising the no-treatment route may ignore this fact.

I made the choice of another year on 'maintenance' because I was able to celebrate a grandchild's eighth and ninth birthday, another grandson's graduation from college, visits with family and friends in France, (with wheelchair), visits with friends on the East Coast (my daughter drove, with wheelchair)... I carefully scheduled the trips during the last 12 'decent' days of the chemo cycle... yes, the good days made it worthwhile (Julia).

Those with stage IV cancer are essentially living with a chronic disease. The survival rate is quite low for those with metastasis, breast cancer that has spread to other areas of the body, although survival time is increasing. About 20% of those with metastasis will live beyond 5 years (Love, 1995). Women at this stage are encouraged to think of their breast cancer as a chronic illness (Mayer, 1997). Unlike early stage cancer, women with advanced disease may experience symptoms from their cancer. Women with stage IV cancer have reported feeling sick and nauseous, dizziness, difficulty breathing, and bone pain (Nuland, 1994; Love, 1995). Chemotherapy, radiation and hormonal treatment may keep tumours and bone metastasis manageable for months or years. A small percentage of women with metastatic cases, between 10-20%, have also had durable remissions with treatment, even at stage IV (Love, 1995).

Palliative chemotherapy, therefore, is treatment to help alleviate cancer symptoms and slow the progress of the disease. Reflecting on her long-term use of chemotherapy, Julia continued,

I cannot look back and wonder, would I have made it three years without it? According to my doctors, the answer was a categorical negative (barring miracles, which do happen), and it had been my choice to try for an extension of life, even with the debilitating effects of chemo.

Treatment offers a way to stay disease symptoms, and slow disease progression.

Rose was diagnosed as stage IV, with a rapidly growing tumor, which was already inoperable. "I didn't know what to do. I knew that I didn't want to do chemo. I didn't want more surgery. I didn't want radiation. I just wanted the damned problem to go away." Rose was so overwhelmed by the severity of her diagnosis that she considered refusing treatment.

Dr. X talked to me on the phone and described in detail what its like to just let a tumor go. He didn't mince words. He talked about the tumor eating through the skin. He talked about the stench. He talked about the pain that got so bad painkillers could no longer touch it. He did not advise me letting it go. Others on the list wrote me pleading with me to do chemo to stop the hungry beast.

She decided to do chemotherapy, with very good results. The chemotherapy shrunk her tumours until they were no longer detected. When she wrote this post her metastases were under control as well.

I am lucky, very lucky. I know at any time that my good fortune can change. Although I have multiple bone mets, (I) rarely feel pain from them and am on no pain medication. I drive five hundred miles a week to get my treatment in Denver and although its a pain in the butt, I'm grateful that I can manage the trip...Yes, life is good. I'm thankful for it.... Even though I raged against the "white man's medicine" you pleaded with me to try it to stop that which was happening way too fast.... Basically, nobody knows what is the best thing to do. All we can do is what we feel is the best for us. I know that nobody can tell for sure what they'll do when they're facing metastasis. I don't even know what I'm going to .... I really have no idea. Its one thing to look at it from a safe distance, its another thing to have the hot beast breathing down your neck.... for those of us who are helped by tamoxifen or by monoclonal antibodies or by dietary changes, terrific, lucky us. For those of us that these treatments don't work, well, its sad (that) maybe the chemo has some side effects but its a lot better than spending our last days in pain and agony.

Rose talks explicitly about the pain that can be brought on by cancer, and characterizes it in frightening terms, as a "hot" and "hungry" "beast". In her narrative, side effects of treatment are portrayed as minimal compared to the effects of the cancer. The disease, rather than its treatment, is the greatest intrusion. The treatment has also

proved effective in shrinking her tumours and, in doing so, restoring to her a sense of normal life; enough that she can drive 500 miles a week, and feels that her life is good.

Posts about metastatic breast cancer indicate that women gradually realize that there will be a time when the disease cannot be controlled, whether this is a matter of months, or years. Eventually they will stop responding to treatment or will no longer be able to tolerate it. How treatment will affect the end of life is a concern for them as well. The availability of treatment makes women wonder if they will know, as Julia said, "when to let go." Women on the list have commented that they are not sure how far they'll go, or what they will pursue if their current treatment stops working for them.

These decisions are made one at a time, without looking too far ahead. However, there is an awareness that at some point more treatment is too much, and women on the list have wondered if they will know that point when they come to it. What they wish to preserve is not the hope of recovery, but hanging on to a near normal life for as long as possible. These issues were acknowledged but not really addressed on the list, perhaps because the goal of life for those with advanced cancer is managing the everyday, and living in the present. As long as treatment permits them to do this it is enabling that goal, and that makes side effects tolerable.

## **Conclusion**

In this chapter I have used narratives about treatment decision making to show that women on the list evaluate their choices according to their own situation, including their hopes, beliefs, and personal values. We are socialized to entrust our health to the medical profession, but once diagnosed with a serious disease many women realize that

medicine does not have all of the answers or treatments they expected. It is difficult to make decisions about breast cancer treatments, because no one wants to make the wrong choice (Charles et al., 1998). Being well informed about the medical options available is one strategy for ensuring the best treatment decisions are made. However, a woman's own needs and priorities will always enter into the decisions as well.

During my time on the breast cancer list, I noted how the list culture promotes informed, self-aware decision making, and the idea that what is right for the patient is ultimately the right choice since the scientific information available cannot determine any individual's outcome. I also noted that in this forum, disclosure is important when giving an opinion. Women there will typically preface their posts in these conversations with lines like, "I can only tell you what my experience was..." or they might say, "This was my experience with chemotherapy. Yours could be different." In addition to sharing information, these women are sharing their personal experience and point of view. In order to validate their decisions they will view treatment in terms of their own situation. As a result, treatment takes on different meanings for different women. There are discernible themes in the reasons women give for their choices when they report on their decision making, and in how they portray these decisions.

Those who invoke a "hard fight" approach look upon their post surgery treatment as insurance against a recurrence. This is particularly evident in discussions of chemotherapy. They are hopeful of long-term recovery, or a remission that would grant them more time. Treatment is literally experienced as a fight against cancer, and as such is not necessarily evaluated on its own merits, but as a means of minimizing their risk and gaining some advantage over the disease. Any statistical advantage, however small, is

perceived as an advantage to them personally. To feel secure in their own mind, they need to know they have taken advantage of what is available. If the treatment fails or a recurrence does happen, they feel at least they will know they did everything possible. Therefore, the risks of medical treatment are minimized compared to the risks of not taking it. Those with metastasis who opt for palliative treatment at least have the satisfaction of knowing it is doing something for them. *Maintenance* treatment is a means of coping, and prolonging life.

Those who opt to forego adjuvant therapy or stop chemotherapy or other treatments have a different evaluative perspective. For them, the illness caused by chemotherapy and the side effects and health risks posed by radiation and hormonal treatments do not balance out the potential benefits of these treatments. Chemotherapy, particularly, causes some women to evaluate the risks and rewards and decide against it. Doubts about effectiveness are weighed more heavily in narratives by these women, as is the reduction in quality of life. They adopt a "no regrets" attitude about their decision. For these women, refusing treatment is not giving in to, or ignoring, the disease but rather, they have a strong sense of what they want their everyday life to be like, and this requires being free from the physical and emotional demands of treatment and medical management.

Women who refuse treatment may look at their bodies in a way that is counter to the medical perspective. Some on the list have expressed concern about the compromising effect that chemotherapy has on the immune system and overall health. Instead of using medical interventions some believe that the best way to handle disease is to strengthen their body's own defences, particularly the immune system so that it can

fight the disease. They may be more likely to seek alternatives that are consistent with their own views about their health and illness. Many of those coming from this perspective accept some treatment, but have established limits (i.e. radiation or hormonal therapy but no adjuvant chemotherapy, or chemotherapy but not HDC).

Recognizing the personal context for treatment decisions helps to explain why a woman with stage I primary cancer might wish to have the most aggressive treatment available to her, despite the side effects, or why a woman with metastasis would refuse to have anymore chemotherapy. It also illustrates that the side effects from cancer treatment are interpreted as more or less tolerable depending on the risk and symptoms they associate with their cancer. Finally, while the medical profession treats side effects from treatment as inconsequential, they may be the focal point of the illness experience for women, and symbolize the way in which cancer has taken over their life. A woman may re-evaluate her perspective and make different decisions, as her illness changes.

## Chapter Four

### Living with Uncertainty and Disruption

"Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick" (Sontag, 1978: 3).

Women on the breast cancer list discuss how their illness has affected their daily lives, and they recount their frustrations with trying to keep up a normal life despite the challenges they face. Cancer challenges one's feelings of security and certainty about one's health and imposes urgent demands. As a result, an ill person's relationship to herself and her world changes (Charmaz, 1991). The breast cancer list is a place where women can articulate their problems in these areas and find understanding. Others there understand bad days when coping with illness or its aftermath is overwhelming, and the many ways that breast cancer can take over one's life. They can offer the kind of support that family and friends may not be able to, because loved ones may need, above all, to normalise the situation (Hilton, 1996).

As Sontag (1978) notes, all human beings have access to two worlds, the sick and the well. We expect to live our lives in the kingdom of the well, visiting the kingdom of the sick briefly, at the end. This does not describe chronic illness; its location is somewhere between these two kingdoms, and it has something in common with both. It is described by many on the breast cancer list as living in a kind of limbo, or "always waiting for the other shoe to drop."

Such metaphors as *roller coaster* and *journey* are often used by breast cancer survivors to describe their emotional experience of cancer. The first metaphor suggests

an existence marked by constant change, with fluctuations in health and well being, and the emotional highs and lows that accompany them. The other presents cancer as a transformative experience; a series of changes, with a beginning and end. Breast cancer can bring positive as well as negative experiences (Coward, 1990).

Women on the list reported that they have had to alter their expectations, and accept a higher level of uncertainty about the future. They have discussed the ways in which they have had to make adjustments in their lifestyle, sense of self, relationships and social interactions. Everyday life can become more complicated, particularly during treatment. Women have written about the changes they made after being diagnosed with and treated for breast cancer. Physical and emotional needs resulting from their breast cancer have made some reprioritize. These survivors work to construct a new definition of normal life that accommodates illness and uncertainty, even as they struggle not to be defined by their illness.

## Illness Experience and Loss of Self

For those with a serious illness, the standard for wellness is the way they were before they got sick. However, illness can cause permanent changes--physical changes caused by treatment, and the emotional impact of dealing with a life threatening illness--that challenge a woman's perception of her self. The lasting impact of breast cancer creates the need to recognize the ways in which recovery, or the periods of wellness which accompany remission, differ from the pre-illness state. Many breast cancer

survivors have commented that cancer doesn't just change how others see them, but how they see themselves. Making sense of one's illness, and the before, during and after of breast cancer requires women to re-write their own biography to incorporate their illness to adjust their expectations of the future (Williams, 1984).

List members have described their breast cancer as a loss of innocence. They are aware that cancer has given them a feeling of vulnerability that others may never experience. As one woman said, "I used to mistake the trivial for serious. Now I know the difference" (Marian). There is a lingering sadness and resentment about losing that feeling of security that comes from being able to expect good health as the natural requisite for everyday life and life plans. Breast cancer abruptly interrupts the natural rhythm of life. Often women are in a very productive period of their lives, wrapped up in concerns such as career, family, and education. Women writing to the breast cancer list express how they miss being able to take feeling well for granted, particularly when they have to adjust their lives in specific ways. The interruption of life plans, loss of femininity, and premature menopause are focal issues in these discussions.

### *Reconciling Illness and Identity*

The sick person is the sick body and also recognizes that he or she has a sick body that is distinct from self and that the person observes as if it were someone else (Kleinman, 1988: 26).

In a post to the breast cancer list, Annette described her feelings of loss as a result of her diagnosis and treatment. She echoes many women's feelings, but I was struck by this post because she literally sees herself, her true self, as divorced from all that has happened to her with her treatments. Breast cancer has deeply affected her sense of who

she is.

I seem to put "me" away, when being treated, because I do not want "me" to see what is happening. I allow "myself" the luxury of hiding to keep safe. But when all is over, I sometimes forget to bring "me" back. This is especially true this time around. Though I was treated with respect and love throughout all my treatments this year, I really had to hide from myself.

It is hard to witness what this disease has done to me physically and emotionally. To look down at myself, I see scars from a port (that is still in place), scars from the hickman (gone thankfully), scars from the mrm (breast reconstructed expertly, but still not "me") and scars from the tram (abdominal). I see bloating from the steroids, fat where muscle used to lay, baldness, discolored skin etc. You all know what I mean because we have all seen some aspect of what treatment does to us. Inside me, I see the withered husk of who I used to be. I do not feel like the vibrant woman I once was two years ago, I still feel like the patient.

I guess the next step on the road to recovery is to help myself. I know I have made a step forward by acknowledging that this problem exists, now I have to try to "fix" it. Right now I am working on the vanity issues, hoping that if I can make myself look better outside, I will start to absorb it. I "know" deep down in that husk within, that I am a very worthy person. One who loves her children fiercely and her husband tremendously. I know I am a good friend and daughter. I know that I am a good sister and Aunt. I just have to find that person again. The one who loved to go for long walks alone. Read trashy books. Chase my husband around the house. The one who used to feel sexy and pretty and intelligent all at the same time. The one who had a career that meant something to her. She is there somewhere and I WILL find her again (Annette).

Coming out of treatment, and immersion in illness, leaves a cancer survivor wondering where to begin. She no longer looks or feels the way she used to, but she longs to get back to the easy fit between her physical self and her identity, her inner and outer worlds. Annette characterises her pre-illness self as "vibrant" and her post treatment self as a "husk." Furthermore, she sees her real self as having nothing to do with cancer. Although some things remain the same, namely her ability to care for others, she no longer looks the way she used to, or is able to enjoy simple aspects of life as she did before.

Body image is an important issue for breast cancer survivors, one that clearly

illustrates the links between the body, self-identity and social identity (Clarke, 1985; Ganz, 1996; Williams et al., 1999). What Annette is most concerned with is what *she* thinks of herself, and how she falls short of her pre-illness conception of herself.

Surgery, and the loss of a breast(s) can leave a woman feeling deformed. We live in a society that is very conscious of looks, and breasts are sexualised. The loss of a breast doesn't just have an impact on younger women. Research shows that elderly women mourn the loss of a breast just as much as younger women do, showing that even those well past youth are conscious of their appearance, and breasts are an important symbol of womanhood (Ferrell, 1997, 1998; Love, 1995).

Chemotherapy can cause premature menopause, which in addition to the discomforts of menopause can raise fertility issues for women who had planned to have children. Women diagnosed with breast cancer in their thirties or early forties abruptly find that this is no longer an option. Once initial treatment is over and worry about survival lessens, infertility may represent the greatest loss for a breast cancer survivor.

I used to look forward to bearing and raising children. Now I mourn the children my husband and I will never conceive, because chemotherapy has thrust me into early menopause. Dare we adopt? What are my chances of living long enough to raise children? There is a big empty hole in my heart and I do not know the right thing to do (Marian).

The circumstances of Marian's life have changed because of her illness. Early menopause and the inability to have children have meant that she must give up a vision of herself she held dear, and the family that she wanted. In another post she said that infertility has been the hardest part of her illness to deal with, and one that is not widely recognised. Breast cancer survivors may feel that they ought to feel grateful to be alive, and that the impacts that the disease and treatment have had on their quality of life should be minimized because, in a life or death equation, they should be minor (Ferrell, 1997, 1998).

### *"Chemobrain" and Identity*

Recent studies have looked at the possible link between adjuvant chemotherapy and impaired cognitive function (Schagen et al., 1999; Ganz, 1998). Noting that memory and concentration problems are frequently reported by cancer patients treated with chemotherapy even years after treatment, Schagen et al. (1999) found that there was in fact a higher risk of cognitive impairment in this group. I found no references to this in the psychosocial research on quality of life and breast cancer, which may mean that this research is not attuned to this problem.

A number of women on the breast cancer list complain and joke about lasting symptoms of cognitive dysfunction, which they call "chemobrain". These include symptoms of short-term memory loss such as being unable to recall names and needed words, and not remembering other details as well as they once would have. Jen referred to this as "oopsitis" and "get there and then what." A teacher of learning disabled children, she found she developed characteristics similar to those of her students, such as leaving the endings off of words when writing. Other list members also report a general feeling of slowness, confusion and low energy. One post illustrated this, and its impact on a cancer survivor's sense of self.

I've been mulling this one over and over again in my poor defective brain. Part of it is that I don't even think to mention problems that my docs don't ask about (which is why they should ask in the first place). The bigger part is that I really am "not myself" and have not been for the 5 years since my diagnosis. I "only" had regular dose CMF so I don't know as I can blame it on that or chemopause or just ageing (but I'm only 56). But I definitely notice that my thresholds-- emotional, intellectual, physical, etc.--are lower. Given the slightest bit of stress I just totally lose it, can't cope, can't think... I'm feeling really awful right now. Probably no one even notices but me. There was a time when I took great pride in the fact that it always took two people to replace me when I left a job; my pinnacle of craziness was reached when it took three people to replace me. I have slowed down since then and probably am doing one person's job quite well. But to me it feels like my head is in molasses and I just can't think (Holly).

Holly's post illustrates three common themes in posts about the cognitive after effects of chemotherapy. First, that these symptoms are not regarded as a serious quality of life issue by the medical profession and are not necessarily asked about during regular appointments. Second, that they are lasting symptoms that impede a return to normalcy after therapy is complete, and finally, the most disruptive aspect of chemobrain may not be how others perceive a woman with these symptoms, but how she perceives herself.

Literature written for women with breast cancer emphasises getting back to normal, and regaining pre-illness energy levels (Rosenthal, 1996). Those who do not return to their "old selves" must adapt to their decreased level of functioning and productivity. Even though Holly has returned to normal life and is cancer free, the physical after-effects have disrupted her life. Treatment has marked a transition in her ability to be as productive as she once was, impacting on her self-esteem and identity. As she describes it, her "emotional, intellectual, physical thresholds" are lower, and this is particularly evident to her at work.

What Holly misses is those parts of herself she took pride in: quickness, efficiency, and the ability to accomplish challenging tasks. She notes that she still feels she is doing "one person's job quite well" and others may not be aware of the problem, but she misses the sharpness and edge she once had, with her previous energy levels and mental clarity. The workplace gives clear evidence that tasks that used to be manageable no longer are, and personal standards of competency and excellence may have to be lowered. Another list member wrote about her experience in the workplace after chemotherapy.

This feeling of inadequacy is just awful, isn't it? I always prided myself on multi-tasking, having an exceptional memory for details and for being a quick learner. My job is/was extremely technical and when I went back to work last year I felt frozen in place because I just couldn't do it. I was able to 'get by' for a while but it was beginning to be apparent. I went back out on disability for reconstruction and other stuff and haven't been back yet. I probably will take the retirement package

being offered but it's like I'm leaving in a state of disgrace (my view of me) and that I somehow just wasn't good enough to keep up or do the job. This was all exacerbated by the young 'hot shots' who were coming in with seemingly photographic memories, superhuman powers of concentration and unbelievable stamina (that) left me in the dust (Emily).

Rendle (1997) found that breast cancer survivors reported that fatigue, decreased ability to perform tasks, reduced stamina, or further illnesses secondary to continued treatment were all physical barriers to returning to former employment. If work and our career play a major role in defining our identity, then not being able to 'keep up' or maintain standards can be very damaging to a woman's vision of herself and who she is. It is also hard to accept a loss of control in the area of mental ability. "One of the reasons I've now applied for disability retirement is because I did not feel that I was able to be the teacher I have always been. It struck me when I had conferences with parents that I really couldn't remember which strengths and weaknesses went with which child. This has never happened to me before these last several years of chemo" (Jen).

### *The Fear of Recurrence*

Focus on survival, and curing cancer, may distract both physicians and patients from long-term quality of life issues when treating cancer (Ferrell, 1997, 1998; Spiegel, 1997). It is likely that patients often underestimate the lasting impact of their disease and treatment, and regard it simply as an obstacle to get past (Utley, 1999). Further, the effects of breast cancer are not just physical, but also psychological and emotional. Even those who are disease free after their treatment for primary cancer will be conscious that disease could return, leaving them feeling that a recurrence may always be right around the corner.

Living a normal life while being alert to new signs of disease is challenging for those who have been treated for breast cancer. It means attempting to progress with an everyday life of family and work, and short and long-term plans, with no certainty that their health will continue and the disease won't progress. This creates a heightened

awareness of their body and health, accompanied by a new caution and mistrustfulness. Cancer survivors may find it difficult to put their fear in perspective, or they may be afraid to resume normal activities, in case the wear and tear of normal life somehow brings on a recurrence (Ferrell, 1998).

Regular appointments and ongoing treatment are permanent reminders of their new and uncertain health status. Breast cancer survivors writing on the breast cancer list often speak of a loss of innocence which results not just from the knowledge they have a disease, but the discomfort and disarray which result from treatment, and the realization of their own mortality. Their feelings are reinforced by regular tests for signs of cancer, CAT scans, and mammograms. For these women wellness is no longer automatic, and the future is no longer perceived as open-ended. Instead, it is divided up into chunks of time punctuated by check-ups that mark time away from the cancer.

"Today is the 5th anniversary of my breast cancer diagnosis. I am trying not to think about it as I knew way too many people who made it that far and no farther. But the truth is that I am alive and well..." (Holly). Check-ups are stressful because each one is a moment of truth, when a woman finds out if she is well. Some women see their physician as often as every three months and any breast cancer diagnosis necessitates yearly mammograms. Instead of trusting that they are well because they feel well, women must continuously prove that there is no sign of cancer.

Even if life returns to everydayness, with future plans and the usual pursuits, any sign of disease can quickly interject, taking top priority and threatening to create havoc once again. The fear of recurrence is chronic for many, even if the disease never returns.

Isn't the process of going to find out what, where, when, maybe even why and how the most frustrating part of this? The past 5 weeks I spent with tests, more tests, surgery, more tests and than finally the "good" news that it's not cancer just about did me in. I liken it to how, when I was a kid, I would put a stick in an ant hill and jiggle it around. All the little ants would come out running around madly, waving their little antennae and (in my imagination) shrieking about how the world was coming to an end. Then, slowly, the ants would realize that the world

wasn't ending *this* time and return to their little tasks. Only now, when the ants come running out, they are shrieking "Omigod, it's a recurrence!! Run for your lives, its cancer again." Then more tests come back and gradually the little ants realize that it was a false alarm and go back to their little tasks ('til next time) (Emily).

As Emily's post illustrates, vigilance creates a feeling of perpetual emergency. A cancer survivor must feel ever prepared for the crisis of recurrence. "Cancerchondria" is the term used by list members to describe their anxiety about recurrence. Any new symptoms prompt a self-evaluation of whether it is likely to be a sign of cancer. Depending on the individuals' symptom and level of anxiety, this is likely to be followed by a wait and see period, and then a decision about what professional advice to seek out. Not only is the breast cancer survivor engaged in a type of self surveillance that probably did not happen before cancer, but all aspects of her body's functioning, and in a larger sense, her life, can be divided into those that are cancer-related, and those that are not.

One example of the way in which disease is filtered through personal experience is cancer patients' interpretation of bone pain. There are frequent references to bone pain on the list, but the main concern is not the pain itself, but its origin. Arthritis is the most common non-cancer related illness experienced by women with breast cancer (Silliman et al., 1998) and it is cause for celebration for a breast cancer survivor because it means that the pain is not cancer-related. There have been numerous relieved, even gleeful messages on the list announcing that a list member's pain was caused by nothing more serious than arthritis. As one woman noted, "You don't die of arthritis."

## **Illness as Negotiation: A Different Kind of Normal Life**

As I have discussed in this chapter, breast cancer narratives express some disorientation, as women discover how their illness experience has changed who they are. Survivors on the list also report that it is necessary to make changes to their lifestyle, and how they live in the world. Illness makes their life more difficult, as it requires planning around periods of wellness and treatment sessions and medical appointments. Coping with cancer can mean becoming immersed in the many tasks that patients have to perform, at a time when they have little energy. Changing diet or lifestyle, co-ordinating family and work responsibilities with new needs and priorities while dealing with the exhaustion and sickness caused by treatment. A patient's world literally becomes re-organized around living with cancer.

Friends, family members, and colleagues may have difficulty understanding this, or may wish to minimize the impact of cancer on their loved one and themselves, to normalize the situation (Hilton, 1996). Cancer is threatening to people as it symbolizes crisis and lack of control. Even those who are past treatment are still in the process of dealing with their illness, and find that those around them do not recognize that it is not so easy to just return to normal life. Marian wrote to the list about her experience with friends and family who wanted her to return to "normal."

After lots of trial and error and tears and anger I've found that the response that works best for me is a firm explanation that the definition of *normal* has changed. I am not and never again will be the person I used to be.

Marian feels strongly that the changes caused by breast cancer make it impossible for her to return to what used to be normal, and that because of this she is set apart from those who have never experienced serious illness. From the narratives on the list, it is

evident that those with breast cancer live with a new rhythm, new needs, and priorities. Sometimes they are sicker than they are at other times, and cancer interferes with different aspects of life to varying degrees. Although they want to assert an identity that goes beyond that of "cancer patient", they also have to deal with the changes. This creates many different challenges and tensions.

*"Cancer is a full time job"*

Mayer has said that after her diagnosis she felt what she describes as the "imperative of illness" (1993: 62). The focus of her life changed as it was taken over by something larger than she had experienced before, something that gave her a sense of crisis. As I discuss later in this chapter, this can lead to different personal priorities, as the cancer patient becomes accustomed to meeting her own needs. The daily disruption created by illness makes cancer an imperative in a different sense. While those with breast cancer struggle to maintain their normal life, they also have the task of being a patient.

Parson's "sick role" concept has become a staple in the sociology of medicine, and continues to influence how we discuss illness (White, 1991). Parsons' model describes illness as a kind of social deviance, demonstrated in part by the fact that a person who is ill cannot perform their normal social role. From this perspective, illness is interpreted as separate from normal life, with patients exempt from usual responsibilities. This best describes an acute illness, which results in a change in roles until the person is well again (Brody, 1987:36) but has been shown to be inadequate as an analysis of chronic illness (Bury, 1982).

Although cancer can indeed be experienced as a crisis, it is not, for most people, something that will remove them from everyday life, or absolve them of usual responsibilities or social roles. Part of the stress of cancer is the tasks it creates- the

appointments, treatments, research, and expense involved. Coping with these new responsibilities means that cancer is not experienced as a departure from normal life so much as an overload of tasks and need for re-organization, combined with a reduced ability to cope.

When I whipped my day-timer out with a pen and highlighter for my first radiation consultation and appointment set-up, the nurse said, "All the breast cancer patients here seem to be so organised, it is just wonderful." To which I replied, "Thank you for the compliment, but there is really nothing wonderful about what I'm doing- I just know I will forget by the time I get to my car if I don't write it all down." She seemed surprised until I pointed out that on top of the stress and trauma of having cancer, losing a breast, (and) going bald, we get drugs to fight cancer, more drugs to prevent the side effects, and now we also have the responsibility of taking care of our appointments, researching and understanding various treatments while many of us still have to keep up with kids, husbands, and sometimes even parents not to mention household responsibilities and a job. I think she quickly saw she had mistakenly sent me down the wrong road with what she meant to be a compliment, so we went back to the task at hand of scheduling appointments and me writing it all down and highlighting my radiation boosts.

Lana's story-telling here illustrates how the nurse does not realize until it is pointed out to her that cancer treatment imposes great demands in terms of time and organization, which patients must strategically work into their already busy lives. List members have discussed how the repetitiveness of appointments and sessions of treatment imposes a different kind of time schedule, and all other work and family obligations have to be made to accommodate it. Anticipating these check-ups and sessions of treatment, and then recovering afterwards, use up chunks of time and demands a woman's focus, so that other aspects of her life must be worked in peripherally. This was evident in the recurring jokes on the list about abandoning housework.

One of the most unsettling aspects of a serious illness like breast cancer is that no one knows what comes next. Women may not know what to anticipate. In a study of narratives by women who had chemotherapy-induced alopecia, some expressed shock

that their hair fell out all at once because no one had told them this was how it happens (Williams et al., 1999). Messages to the list often conveyed this sense of navigating uncharted territory.

For me, the terror is in the "not knowing", the surprises that keep cropping up... for example, If my doctors had been honest about the level of exhaustion that one might feel while in chemo, I would not have felt that there was an innate weakness in me. After all, they all mentioned patients who worked all through chemo. However nobody offered an opinion about how sick one can get in a primary level classroom... how debilitating standing for 6 hours a day can be and, yes, that's why your ankles are the size of your thigh (Melissa).

Planning around the body's new contingencies creates a sense of lost, or misplaced time due to reduced productivity. There will be periods of relative normalcy interspersed with periods of sickness; for example recovering from chemotherapy, bouts of lymphedema, or pain from metastasis. List members complain they can no longer plan very far ahead, or they make plans that cannot be carried out.

This has been one of the hardest things to accept about this disease, in fact, I have not accepted it yet. I am too scared to plan any further than a few months ahead. In fact, while I am on chemo, I often find that my plans for the next day can't even materialize! But I plan anyway and try to remain flexible (Bonnie).

This woman continues to make plans that are subject to change. This may mean putting anything that is not crucial, on hold. Relationships, particularly casual ones, may deteriorate because of this, so that the patient finds herself with a smaller social world, (McEntyre, 1995) which must be much more accommodating and flexible. People vary in the extent to which they accommodate the new demands on their time, or hold to former standards and expectations. Nadine wrote to the list that she found her normal activities exhausted her. "Maybe I am just too unwilling not to do things because the reason in my mind would be *cancer*. If it was just my natural laziness going on, I would

feel better about quitting perhaps." Spending more time on their health and being sick or just less productive are impositions that do not sit well with some, especially as they are constant reminders of breast cancer.

The extent to which patients are able to access material resources and other sources of support will affect the flexibility they have. For example, if a woman is able to have down time after treatment, get help with family responsibilities and delegate tasks and responsibilities to other people, her illness will be more manageable. The more support a woman has and control over her life, the better able she is to accommodate her illness and minimize stress and lost time (Bury, 1982).

*"Everybody is acting as if I am cured" (Jean)*

Breast cancer survivors who have finished treatment struggle to understand their health status, and try to resume life as usual even while they realize their disease may return. Friends and family are eager to believe that they are cured, and that, as Jean says, "(Its) just a matter of feeling better and growing back hair." This attitude does not recognise the continued uncertainty that women must live with, the vigilance they must maintain in being aware of any lumps or signs of recurrence, the long term effects of the treatment they underwent, or the emotional impact of their experience.

Women on the breast cancer list discussed how difficult it is for them to acknowledge their experience and how it has changed their lives when others do not acknowledge these as well. Without support, they find it hard to assert their new understanding of their health and their future, and how they differ from their former notion of themselves as normal or healthy (Hilton, 1996). "How do you deal with a

spouse who 18 months after your mastectomy doesn't really acknowledge that you had cancer?... I'm not feeling sorry for myself, honest. I just really think it is hard to go the wondering and worrying route alone" (Dianne).

Although she no longer had any sign of disease, Dianne was still concerned about breast cancer, and wrote about how important it was for her to do the "run for the cure". Dealing with a serious disease and the possibility of death result in a heightened sense of one's own mortality. Even those who are "cured" must deal with the chronic uncertainty they feel about their health (Pelusi, 1997).

As list members have discussed, women are reluctant to believe they are cured because the word is meaningless. To them the word suggests a lack of caution, a disregard for the body's vulnerability. Although a woman may return to work, family, and normal life, she may never again feel that she can afford the same easiness she once had about her body. She is forced to have a self-consciousness about herself, about her life, that may be difficult for others to understand. "Why is it that one of my oldest, well-meaning, loving friends keeps driving me crazy?" Cecilia discovered that she had hematomas in her mastectomy scar which had to be removed, a minor outpatient operation.

So I tell this to my friend, who immediately says things like, well, this is just a little setback. You're cured, you know you're cured. Now you have to look forward, not back. There is life after breast cancer. And so on. Since I say this sort of thing to myself all the time, why does it drive me mad when she says it to me? She has been one of the most supportive loving friends you could wish.... But her permanent optimism is awfully hard to take.

Cecilia, like other survivors on the list, is unable to accept blanket reassurances from those who do not demonstrate that they fully understand or accept the reality of her

situation. Minimizing the fear of recurrence de-legitimizes a breast cancer survivor's fears, and imposes expectations that she will continue to be well. The burden of "thinking positively" may be too much, as this attitude implies that breast cancer can be controlled. This also touches a nerve by suggesting that recurrence is failure, and that any sign of cancer or disease progression is a tragedy, a crisis. For women who live years with metastatic cancer, it is a part of their bodily landscape, and the disease is part of their life. However, it is not their whole life, and they resist being defined by the disease and their prognosis. Sometimes the only way to do this is to act well. If someone looks well, people around her often assume that she is well. Again, this imposes unrealistic expectations and fails to recognise the many degrees of sickness and wellness experienced by someone with cancer.

I find that my dad (whose sister died of bc, and whose brother died of another form of cancer) attributes my health status to my appearance. "You look good" means that he doesn't think I look ill. So as not to worry him, I make the extra effort to look my best when he's around.... Otherwise, I'm my usual self (looking good for me). Isn't that about the nuttiest thing you've heard?" (Tina)

The burden of keeping up appearances for other people's sake is not only emotionally wearing, but it perpetuates the notion that sickness does not have a part in "normal" life; that the fears and concerns of a breast cancer survivor are not legitimate, and that the most important thing is for her to get past her illness by doing everything she can to appear, and therefore be, well. Likewise, women who do look well despite their illness may not have their condition acknowledged by those around them. "Someone finally explained it to me. Cancer patients are sickly looking, weak and emaciated. Since I am not that, I am not really a cancer patient" (Nadine).

Asserting one's new sense of what is normal may be difficult. Others are often reluctant to acknowledge uncertainty about health, the possibility of death, feelings of chaos and confusion, and the lasting impact of interrupted life plans. These things can be very threatening, and as a result will be minimized. It is evident from these posts that these women feel pressure to assuage other people's fears, even while they have to deal with their own.

### *Making Changes*

A serious illness is an ultimatum. The possibility of having less time may give a woman with breast cancer permission to live life according to her own priorities, putting her own needs first. When time is undefined we are less apt to prioritize. A myriad of small daily chores can easily fill time, and women are socialized to meet everyone else's needs before their own. When time is put into question and emotional and physical energy reduced, then there is more prioritisation. Some of these changes are caused by the physical effects of the illness, such as having less time and energy, as I discussed above, but they also have to do with privileging one's own needs and wants.

Women on the list have said that one thing their disease has taught them is that playing it safe and observing social norms and obligations have not protected them from breast cancer. As a result, they stop putting off personal goals, are better able to delegate tasks, and can allow some things to go undone. After a diagnosis of breast cancer, women may reorder their lives to accommodate illness while continuing to live as normally as possible. They do this by prioritizing what is truly important to remain functional and comfortable and dispensing with what is merely obligatory, or doesn't

provide satisfaction.

Depending on the severity of their prognosis, they may be confronted with a shortened life span, and a shorter period of time to accomplish personal goals, or accumulate life experiences. For example, a woman may become more of a risk taker financially or emotionally upon realizing that the end of her life is not just an event that will take place someday, but may in fact take place in the foreseeable future, in her current circumstances. In her book *Death and the Creative Life*, Goodman (1981) asked those she interviewed to consider the fact of their own death, what day of the week it might take place on, and what season. Most had never perceived their death as an actual event that would have a time and a place, but merely a theoretical event that would take place in the distant future with no specific time or circumstance.

Those who are seriously ill still live in the everyday, in fact they often celebrate even the smallest details of everyday life, but they now live it on a broader stage. There is a relationship in their mind between what takes place on a daily basis in their life, and the eventual end of their life. Betty Rollin said about her experience with breast cancer, "My raised consciousness about death has somewhat raised my consciousness about life. There is, I find, a recurring jingle in my head: Am I doing/what I'd want to be doing/if I were dying?" (1976: 205). If a person envisions doing different things, being in a different job, relationship, or simply having achieved greater self-knowledge and self-actualization, then breast cancer can prompt the need to make specific changes.

As Kleinman notes, the persistent re-examination that characterizes the life of a cancer patient can create the opportunity for considerable self-knowledge (1988: 48). Research shows that most women feel that some good things have come from their breast

cancer. In particular, some breast cancer survivors find that as a result of their illness, they learn how to make their own needs and desire priorities for the first time in their life. (Coward, 1990; Ganz, 1996; Pelusi, 1997). In a thread of conversation on the breast cancer list about the good things that had happened along with breast cancer, women told of the ways in which they have learned to take better care of themselves, physically, mentally and spiritually.

Doing things I want to do- I no longer postpone something or say I'll do that another time, especially if its important to me. And I take every opportunity to travel that I can. I have a simpler life, I don't get as much done. I am very selective about social plans and would not think of packing in too many activities- and I enjoy those I do so much more (and housework is last on my list thanks to all the recommendations by fellow listees : ). People I care about are a priority... (I) make myself a priority whether it is my health, my feelings or my relationships; I had a lot of relearning to do as I used to come last... not now or ever again (Rachel).

Rachel has taken steps towards a simpler life in which she feels less compelled to get things done, and has more opportunity to enjoy the things she does. She is now more selective about social obligations, she makes her desire to travel a personal priority instead of saying "someday", and she gives a lot more attention to her own health and well being.

Illness also motivates changes in lifestyle because a healthier lifestyle may result in a better chance against the disease. But these changes also benefit the whole person, and may extend into areas of life that are related not strictly to physical health, but also to mental and emotional health.

At first I was going to change everything, but that didn't work. So I've been focusing on a fewer things... (I) am now happily swimming several times a week, either

water aerobics or laps (my new favorite). It brings back lots of good memories... Eating more vegetables. Many more. And liking it... acupuncture twice a month, singing in choir which I'm convinced is therapeutic and stress reducing, taking in ocean air and sounds, etc. More and more, I'm trying to do only things that I love. I'm also trying to make enough changes and attempts so that I have a chance to find out what I love (Lisa).

Lisa committed herself to an exercise regime that she likes, and finds that she enjoys eating more vegetables than she used to. Illness led her to explore options and adjust her lifestyle in ways that she might not have done otherwise. She is also paying more attention to what her own needs and wants are. Doing things for her health helps her to do things that contribute to her overall enjoyment of life. Interestingly, she claims that singing in the choir is "therapeutic and stress reducing." Probably it is, but this demonstrates how positive life changes are viewed in terms of health first. Reducing stress, doing less, and living well may be more permissible now, because they improve overall health and possibly longevity as well. One list member pointed out how ironic it was that leading a stress free, healthy and enjoyable life is now perceived as a means to living longer, rather than an end in itself. It may be true that it is only when a woman's health has been put into question that she feels the motivation, or even courage, to make big changes in her lifestyle.

Coping with an illness may present a time and space in which to re-evaluate, and make positive changes. When a person can no longer take their life for granted, it puts things in perspective, and different priorities emerge. Some take this as an opportunity, as one list member put it, to "think outside the box" about one's life and future. Life is thought of less in terms of meeting obligations, and more in terms of overall satisfaction

and health. When women with breast cancer realize that they might not live indefinitely, they feel entitled to think more about their own needs and how to meet them. Some find that they are motivated to explore life in a more meaningful way (Coward, 1990).

Some may also find that they have reduced expectations of life. Their needs may be very specific and seemingly fairly small and inconsequential, but they are things that enable well being and quality of life. Things like emotional support, pain relief, feeling well enough to go shopping or to movies, or taking a family vacation, are more important than ever before.

#### *Conclusion: Managing Uncertainty*

Dealing with breast cancer as a chronic illness is helpful to women who are trying to manage symptoms, and live normally for as long as possible. For women who wish to regard it as an incident, or take up where they left off, chronicity presents some problems. The perpetual uncertainty, inconveniences, side effects from chemotherapy and hormonal treatments, and regular check-ups and tests are a constant reminder of the disease. At different times, list members have expressed resentment about the focus that cancer takes in their life, their new job as a cancer patient, and the disruption they experience in the synthesis between their bodies and their selves. Women must incorporate their new reality as breast cancer survivors into their lives. This includes a new understanding of sickness and wellness, a higher tolerance for uncertainty, re-prioritizing, and challenging their own and others' expectations about health.

How a woman deals with the uncertainty that accompanies breast cancer depends in part on the severity of her diagnosis. A woman who has had primary breast cancer

tries to resume her life as before, as a well person, although she may find it very difficult to be confident that she will live a long life. For some it takes years of being cancer-free before they start to feel safe. The continuous uncertainty now attached to the future and her sense of self must be managed on a daily basis and, as such, steps will be taken to either integrate this uncertainty into her world view, or minimize it in attempts to live life as closely as possible to her pre-breast cancer life. Those who are acutely aware of the uncertainty in their lives will develop strategies for dealing with time, and the future. Often, a more intense focus on the present and daily life, and obscuring of the future are what is required, to minimize the level of uncertainty.

Uncertainty impairs one's capacity to get back to normal, it necessitates life changes and can result in change in personal priorities, identity, self-perception and perception of the future. For women with advanced cancer, however, uncertainty is an ally, because the uncertainty of when and how their disease will progress to the end stages keeps knowledge of their disease and life course uncertain, and to some extent, still negotiable. This is clearly illustrated in the extent to which women believe that they are susceptible to random events the same as the general population without cancer. Remission, new treatments, and the inability to predict the course of stage IV cancer contribute to this perception. A few months prior to her death a list member wrote,

I now feel like I've got a shot at the random acts of life and death, i.e. traffic accident, lightning strike. Just like you or my sister who doesn't have breast cancer. Whereas previously I thought and KNEW I would die from breast cancer. I still probably will, but the picture of it all is somewhat different than last year.

Those who experience the greatest uncertainty about their future will develop a general expectation that they will die from their disease. Those with metastatic breast cancer know that this is a condition that generally results in death, although how this will

unfold for them is still unknown, as is the time they have left. These women don't just consider the possibility of their early death, they gradually become convinced of it. "Typically, certain death expectations eventually develop out of situations characterized by chronic uncertainty. Thus the patient moves from facing the threat of death to facing the reality of death" (Charmaz,1980). In the next chapter I will examine these expectations, as they relate to confronting mortality, and coping with terminal illness.

## Chapter Five

### End of Life Issues

After a primary diagnosis a local recurrence or the discovery of metastases are a woman's greatest fear (Ferrans, 1994; Ferrell, 1997, 1998). If a recurrence does occur all of one's hopes for the future are put into question. For those who experience a recurrence of breast cancer with metastasis, their perception of their illness changes. Advanced breast cancer brings different challenges than primary cancer, and imposes a new reality on the patient (Coward, 1990; Lewis and Deal, 1995). Twenty percent of those with metastasis live beyond five years, meaning that at this stage, it is a terminal disease for most. Stage IV breast cancer is often responsive to treatment with durable complete remissions attainable in 10%-20% of patients, although long disease-free survival indicative of cure is rare (Love, 1995). All the things one might have done or achieved later in life, plans such as retirement or travel, the pleasure of watching grandchildren grow, can no longer be looked forward to with any certainty.

Women with advanced breast cancer must find ways to manage their mortality. Mortality is a difficult thing to face, not least because of our culturally ingrained denial of death (Kubler-Ross, 1969). Women are encouraged to treat their breast cancer as a chronic disease, taking away the focus on dying, and putting emphasis on daily management (Mayer, 1997). Eventually, however, end of life decisions must be made, as well as changes in lifestyle and priorities. The trajectory of chronic illness and early death is one that is difficult for loved ones, and even doctors, to acknowledge. All of the

medical profession's resources are focused on prolonging life. There is little discussion or awareness in everyday life of the months or years that some people spend, coping with their illness (Nuland, 1994). Living with a chronic illness that will result in death means accommodating the knowledge that life will be shorter than expected, while still progressing with life.

The women on the breast cancer list who are in this category seem to have few illusions. They do exhaustive research, and they engage in a forum, the breast cancer list, where the reality of the disease is talked about matter-of-factly. Their posts frequently express that while they hope that they will be one of the lucky few who experience an unexpected remission, they also have to acknowledge that they probably will not make it to that 5 year mark.

These women face different challenges in dealing with their diagnosis and their illness. On the breast cancer list, the things that concerned those with advanced breast cancer the most were issues such as how to prepare their family for their death, how to enjoy the present, what treatment to have at the end of life, and how much they wished they could be around for the future. These women may feel that they need to protect those around them, and they themselves also need to feel that death is an as yet distant and abstract event, rather than a fixed reality. Thus, as women become more conscious of their mortality, they develop a different perspective on the future, and a heightened awareness of the present.

### *Adjusting to a New Reality*

One thing with mets is that every waking minute we are looking at death's face... it leers at us constantly. I think everyone with breast cancer, no matter what stage, has had this experience, this fear. But with mets, it's more than just a fear, it's a certainty (Rose).

Some of the uncertainty that I described in the previous chapter is resolved for women with metastasis. For some, now that the worst has happened, at least they can stop wondering if the cancer is going to come back. As Eve said,

Actually, in a strange way, I think I've experienced the diagnosis of mets as something of a relief. (So far, I've been lucky enough to have them confined to the bones...cervical spine in '96, lumbar and sacrum a few months ago.) The 50/50 thing for the preceding several years was very spooky for me. I think because I wasn't, back then, at all good at figuring out what my feelings actually WERE about many things, and I'd long been a somewhat depressive person, with a lot of ambivalence about living and dying to start with. Yet there was all the alienating surrounding pressure to "think positive" (at least I found it very alienating--not least from myself), and with the 50/50 set-up, I was afraid to want or expect anything, at the very same time that I was very unskilled at knowing what I DID actually want or expect....

Adjusting to the reality of terminal disease means balancing the present against the future. Plans do have to be made, which means a woman needs to know how she feels about the prospect of certain treatment options, and preferences about the end of her life. But as Eve noted, there is a limit to how much you can know when you are still feeling well. And although women with metastatic disease research and think about their options, they are also eager to live as much in the present as they can. They still, as Julia said, use a mental "time-screen," to obscure the knowledge of the inevitable and keep dying as a distant event. Therefore, they may plan their life with two contingencies in mind--early death and long-term survival. Said one woman who had had two local recurrences but as yet no metastasis; "I tend to consider "what if" both ways. Now every decision in my life means taking into account the possibility of a future, with retirement

and living happily ever after, and the possibility of metastasis. It is kind of wearying...” (Cheryl).

In narratives about death and dying, much of the pain is attached to leaving loved ones. Those with advanced breast cancer are fearful of the impact their passing will have on their families. This may lead them to make certain decisions, both at the end of their lives and during the advanced stage of their cancer, with the hopes of prolonging their lives, or easing the impact on their families.

Discussion on the list suggested that family members often aren't able to fully acknowledge the reality of advanced breast cancer. In some instances this is because they are not as well educated about the disease, because they do not do the research that the women themselves do. Or they may be at a different stage in terms of acknowledging what is going to happen. Women with breast cancer need room to negotiate the feelings they are having. They may be overcome by grief at unexpected times, as aspects of ordinary life only serve to remind them of their shortened life span, and the fear and denial attached to dying. Again, it is a question of how comfortable they are expressing their own needs, and the extent to which they are able to deal openly with their fear and grief.

Sometimes what is uplifting and encouraging for us is painful for our loved ones. I love the theme from the movie Titanic, “the Heart Goes On.” It gives me comfort to think of going on in the hearts of loved ones- my husband can't listen to it without crying and says “at some point it may be comforting to me too, but not yet, so please listen to that song while I'm at work for now” (Lana).

There is emotional work in dealing with the knowledge of one's disease, particularly if loved ones cannot yet deal with the prospect of losing their partner, mother, sister, or friend. In another post, Lana noted that when people asked her how she was

after her last round of treatment and she told them honestly what her diagnosis meant, she was often met with a reaction of shock. It can be very threatening to some to realize that someone that they know is dying. They only want to hear good news, and filter updates for optimism. An individual's social world may consequently shrink, not only because her energy is limited, but also because some friends and acquaintances cannot cope with the knowledge that someone they know has such a serious disease, or with being confronted with mortality in such a personal way.

In addition to protecting loved ones, women on the breast cancer list discussed their ambivalence about the future. In their narratives they express how hard it is to see others making future plans that they may not live to see. It is also difficult for their spouses or partners to reconcile their need to plan for the future with the knowledge that their partner will no longer be there. List members with advanced breast cancer report feeling conflicted about being drawn into these plans. Planning for a future they are reasonably certain they will not have is painful, and seems like a waste of energy. Further, it is a reminder that those around them have a different perspective on the future. They know they will see the millennium, retirement, children's graduations, marriages and grandchildren. Those with a serious illness can no longer anticipate these time markers with the same confidence, and envy those who can take the future for granted.

I, too, think about the millennium with mixed emotions. Yes, I want to wish, dream, plan, and build for my future, but many times, I feel it is for naught. I feel defeated, when my husband mentions "retirement", long term investments, future trips, and my daughters' future. Will I be here to see those days?

Sometimes I wonder why am I working so hard to save "for the future". I need to do this, I know, but I hate thinking that all this hard work will not have been for me. Who will reap the benefit of my future plans?

Isn't that horrible? I want to say to my husband... stop fretting over this or that

because, in the long run it does not matter to me. But that is wrong and unfair to him. I hate that!

So I try and strike a balance between the here and now and life far off. I can still have dreams, and I do. I have attained some of my dreams already. I sometimes feel I am running in a marathon, trying to do so much in one day or week. Feeling that if I put something off, I will never get to do it. This, living with breast cancer, is truly "life in the fast lane" (Annette).

Like Annette, Bonnie also experienced some conflict between the need of family members to anticipate the future and her own need to concentrate on the present.

.... I too get envious when anyone talks about the "distant" future... the millenium, this summer's holidays, my kids' career choices (they're only in grades 7 and 9), and retirement. I especially get sad when my husband and I talk about our retirement savings. And this makes me angry too because I feel that some "other woman" will be benefiting from all my savings! Isn't this bc just the pitts?! (Bonnie).

However, no one on the list promotes staying at home and waiting for the inevitable. Rather, they advocate living within the limitations of their disease, but challenging them. A good example is Nadine, who has lived several years with a stage IIIb diagnosis, which is longer than her doctor thought she could.

I won't live forever. No one does. But when I didn't believe the statistics because I just felt healthier than the doctors told me that I was, it appears that I was more right than they were. Certainly, I have lived a life very much living, after a very serious diagnosis, and am still going after the five-year mark. (May the evil eye not hear, but I hope that people do have more hope. Hope is never wrong in my honest opinion!).

Nadine wrote to the list about how she felt when someone told her that she was brave. This is has been a subject of discussion on the list more than once. Those who have written about it feel that these comments, while well intentioned, show a lack of understanding. People with breast cancer don't choose to have it, and once they get it, they deal with it as best they can.

Anyway, anything someone diagnosed with bc does is brave, often including getting up in the morning.... But another response I had to the comment (mentally, of course) is that, what else am I supposed to do with my time? I was basically told that my number was up over five years ago. After a certain amount of time, it is worse than useless to just do nothing, while waiting to see when my number really is up. (You know what I mean, don't you?).

Like Nadine, those who are asymptomatic or have manageable symptoms can continue with work or personal projects and commitments. These women maintain relationships, do those things that are pleasurable and which bring them near to their family, friends, and loved ones. They express that the main difference in their life after the recurrence is that their focus has shifted from future attainments to life experience now.

No, life is never quite the same after a breast cancer diagnosis. Our thoughts of dying somewhere in the far future are not quite as fixed as they once were. Everyone will die some day, but one day we have it put right in our faces. I have found for myself that staying in today (the best I can) is very helpful. I try to cross each bridge as I get to it, and I try not to write "scripts" for my life (Colleen).

This may mean letting go of some expectations and deliberately not planning far ahead because that gives a greater sense of flexibility, instead of being confined to a vision of the future which is no longer applicable. Chronic illness prompts decisions as to what plans to hold on to, in the interests of living life to the fullest and progressing with living as long as possible, and what plans to leave aside, as no longer relevant. Instead of saving for retirement and the future, list members have said they opted to travel, retire early, and do other things that they can do in the short term, but would not be able to afford over the long term. On a daily basis, they are more likely to prioritize and decide what is truly important and necessary and let small details and distant worries

go. Many concerns are not worth compromising quality of life, mental peace of mind, or wasting limited time.

Women discuss what a strange experience it is to realize that their family has a future that they won't share. This is a great cause of stress for them, knowing that they will have to leave their family, and the absence that will create. In a conversation about remarriage of widowers, Lana speculated on what her husband would do in the event of her passing.

Knowing my husband, he will not be ready for a while and most likely would look for someone who is first a friend since that has been the basis of our very successful marriage. I hope that any woman after me would have the good sense not to try to compete with a memory. I have had talks with my husband about this and I know I will live on in his heart. There will be special dates and occasions when he will need to visit that room that I occupy in his heart. I hope he finds a mate who can understand that love is not quantitative, that it has no bounds and is large enough to accommodate many including, I hope, my sons. The ideal person will be one who will not envy our life together or what we had, but who will celebrate and build something unique for them- maybe even regard me as a friend.

### *The Importance of the Present*

Terminal disease alters one's sense of time, and puts strain on the present especially. This can make the present more enjoyable, by highlighting the joys of everyday life. A woman with advanced disease may decide to stop putting off plans for later, and become more conscious of living fully. At the same time, disease can make the present very stressful, as she may feel she has to fill it with all the living they had anticipated for an entire lifetime; life experiences, time with family, and happy memories.

One argument about death, based particularly on accounts of dying by artists and scholars, is that the approach of death gives living vitality. Once time is short, people may live with particular intensity, and through that gain insight and self knowledge

(Broyard, 1991; Goodman, 1981; Lorde, 1980). This view portrays cancer as an epoch in one's life, one that may be a conduit for self-knowledge, or what Lorde calls the "considered life".

I am talking here about the need for every woman to live a considered life. The necessity for that consideration grows and deepens as one faces directly one's own mortality and death. Self-scrutiny and an evaluation of our lives, while painful, can be rewarding and strengthening journeys toward a deeper self (1980:58).

A theme that threads through many conversations on the list is that women have noted that they do have a more conscious enjoyment of their life since breast cancer. The awareness of mortality prompts decisions about how to best enjoy life- not some day, but now. One woman on the list gave a tongue-in-cheek account of how breast cancer had changed her perspective on life.

I will not allow myself to be bored. To be with boring people. To do boring things. I will say what I want, nicely. I will not use the chipped plate. I do what I can do, today, and let what I can't do, go. I allow my house to 'be itself' which makes for a happy house. I regard pleasure as reason enough.

This perspective is based on not compromising, but rather putting one's own needs first, and placing emphasis on aspects of life that are most enjoyable.

Nature, personal projects, creative work, friends and family all become more precious with the approaching end of life. Women on the breast cancer list have repeatedly written about spiritual moments, when they found themselves experiencing a walk in the woods, a family event or writing and painting with a special energy, an intensity that they were not aware of before their breast cancer. This is a perspective which has been noted in other research among women with advanced breast cancer (Coward, 1990). Eve is a good example of someone who began to enjoy new talents after

her diagnosis of metastasis, and she describes how her diagnosis was concurrent with a new phase of self-discovery and self-realization.

Another big transition in my life has been, really QUITE suddenly, the discovery or un-folding of a "right brain." For 46 years I'd been a remarkably left-brain gal, totally verbal: I teach English, I write books, I blablablabla for a living and for fun. No music, no art, no nothing but words. Then, absolutely out of the blue, I started wanting to use my hands all the time to make things with. First it was a sudden obsession with painting on cloth with acrylics. (Ugly--don't ask me why that!) Then, all I could think about was cutting up old kimonos and making scarves and quilty things out of them. Then, somehow, polymer clay became the main thing in my life. I'm serious--these were more than hobbies, they were kind of orgasmic grand passions. And all this was happening exactly during the five months that I was having acute neck pain from the unrecognized mets, and treating it (and having it treated by my dumb primary-care doctors) as muscular strain of some kind. I even joked to my friends that the cancer must have returned--in the form of a brain lesion to the Sculpey lobe. (For the Sculpey-uninitiated, Sculpey is the name of one of the brands of divine polymer clay.)

All of which is just to say, that in some mysterious way the cancer recurrence was also part of a process that included/unfolded into an artistic development that took me completely by surprise. It's been one of those spontaneous free gifts that I could never have looked for or expected. Now it's mostly taking the form of textile obsession (weaving, primarily--but still with a lot of kimono materials; currently no Sculpey). Texture seems to be the biggest hook for me, but colour is, too. It feels like the best way I can figure out to be truly alive, now while I am alive, in this life, as a human being, as this particular one. At least, that's my first guess about why it seems so closely related to the Stage IV experience. There's probably more to it than that, though, I think. I still have my day job (in fact I love teaching and writing), but since the recurrence, I've done everything I can to rearrange my life to put the possibility of art-making at the centre of it. I feel incredibly lucky to be able to do this. I know it depends on a lot of kinds of good luck—including that of still feeling energetic and healthy enough. For how long, I obviously don't know....

... To me, there has been something very precious about the post-recurrence experience of living in a pretty intimate proximity with the prospect of dying. So far, I mean. Death has been a very steadying and truth-enhancing thread to have running through my fingers. I don't find that I want to slash at it or be in flight from it, or turn it away. I want to be here with it. But by the same token, this time--this living--also feels new, full of fresh possibility, and very precious. As seldom before in my life, I find I can't wait to see what it brings next.

Women on the list with metastatic breast cancer have said that they experience many events as if for the last time. In particular, there is great stress around holidays, anniversaries and family gatherings, which all provide time markers. These events prompt the question of whether an individual will still be there the next time, or if she will be able to participate. There is an inescapable feeling, which list members have written about, that each holiday may be the last one they witness. Trying to extract a lifetime worth of enjoyment and life experience from the present puts strain on everyday life. Time now matters so much more than it did when a normal life expectancy was assumed. This is especially true for those with young families, who wish to give their children memories that will see them through the grief of their mother's passing.

As I decorated the tree with the girls, I thought... is this it? As I took each ornament out, I treasured the memories. And then I remembered last year and the year before, and how I had done the exact same thing... wondered if this was my last year with my family.

I can feel those silent tears you shed, I have done the same myself. I sometimes just do not want to let anyone into "that place" inside of me that is so dark. It scares them so much; it scares them more than it scares me. So, I carry tissues *everywhere* I go, because I never know when it will hit me. Watching my girls climb on the bus has become precious to me. Oh, and hugging them when they get home is so intense. I love to tuck them in still, and wonder who will continue it after I am gone. Spring concert is coming and June recitals are coming, I will be here for them, I know, but I will be crying my eyes out!

I remember something someone said back before Christmas... make some memories. That is what I am doing. Good memories. I want them to "remember when" with happiness in their hearts. And they will. And though I cry a lot, I am so enjoying this extra special time with my family. I am enjoying the routine, as you are. This is my life, and it is wonderful, but I want it to last forever, and I know it will not. So grab the day, I say, and live, live, live. (Annette)

Being forced to surrender a vision of the future makes the present all-important.

However, the pressure to fit as much living as possible into the present can be very stressful, particularly for those experiencing symptoms.

### *Control at the End of Life*

Control over dying very much depends on the knowledge a patient has of her disease and her own needs. Being informed is very important for making end-of-life decisions (Bull et al., 1999).

There is a tremendous comfort in finding out that others (with breast cancer) have and are now feeling the same way. There is tremendous power in knowing the many avenues that face all of us in the future. There is no promise of "cure" with this disease and no way of knowing or even guessing at the futures any of us might face. There is, however, power in the knowledge we share, power in the preparation for the future and power in knowing what to look for and what questions to ask. When I first faced my surgeon, I lacked this power. I didn't know what questions to ask nor was I prepared for what I would feel. I don't like to think about having to face up to metastasis, but I do feel better prepared, and less frightened. This comfort comes from what I have learned here... (Melissa).

Managing breast cancer means being prepared for the worst, but also maximizing flexibility. Both Glaser and Strauss (1965, 1968) and Charmaz (1980) note the importance of estimations of time in the dying process, particularly in regards to "time left". However, this was not a focus of conversation on the breast cancer list, perhaps because these women were still feeling well and managing their disease. Although they may hold the view that death has a "right" time for them, as Colleen does, some members have said they do not want to know their prognosis, or specific time frames for the end of their life. There appear to be two reasons for this. First, those well educated about their disease know it is unpredictable, and that estimations are best guesses only. Further, those who are dying wish to live, and remain engaged with life, until they die, and not spend their remaining time anticipating their death. Other recent writing about death supports this point of view (Tworkov, 1998).

Prognosis interferes with flexibility and the need to feel that time left can be

negotiated, and is not fixed. This is clearly illustrated in the approach that some take to check-ups, and tests for detecting metastasis. While early intervention can make a big difference for those with primary cancer, it may not make any difference for those with metastatic disease. Regular check-ups may only create anxiety. A thread of conversation on the breast cancer list questioned the benefit of check-ups for those with metastatic disease. Asked one woman, "Given the anxiety that accompanies check-ups, should we abandon them and trust to our bodies to tell us when something is wrong?"

The use of tumour markers to monitor a woman's disease may create a similar situation of anxiety and stress. A tumour marker can be detected in the blood or other body fluids and may be an indicator of cancer cell production. There is some controversy in the medical field over the use of tumour markers. No individual tumour marker is conclusive for cancer, and virtually all are present at low levels in the normal human body, or other non-cancerous conditions (Love, 1995). Efficacy aside, however, conversation on the list indicates that a number of list members do have these tests. Like any test when feeling well, tumour markers for those with metastasis may disrupt a woman's sense of well being. A rise in tumour markers would mean more tests for metastasis, decisions about whether to treat them, and more time spent being a patient.

There are still many treatment options available to those with a diagnosis of metastasis. Tests raise the question of how to manage any disease progression, as the medical profession promotes awareness as an impetus for treatment. Sometimes the only way to circumvent this pattern of treatment is to avoid diagnosis until symptoms appear. Some women on the list say they have made a conscious decision to limit the knowledge that they and their oncologist have of their disease, in order to maximize treatment-free

time. For example, they may decide to forego bone scans and CAT scans that would identify metastasis before they become symptomatic. These list members have decided not to have these tests, and to only go for a check-up if they experience pain and other symptoms. This represents a significant shift to treating their symptoms, not their disease. In the short term, however, it is a decision that may grant more flexibility, normalcy, and quality of life.

Women on the list discussed the ways in which they normalize their situation. One way of managing dying and death is to see it as a natural part of the cycle of life, what everyone will have to go through, even if it is earlier for them. This takes the focus away from disease and illness, and makes it more normal. "I accept that all who are born will die someday. Wish I could have spent more time on this earth, that is for sure, but this is the way it is..." (Colleen).

There is also preparation for the end of life. Anne described her feelings about making preparations for her death. At first she felt that to make arrangements was an acceptance of her disease, that it would mean that she was basically giving up. She later changed her perspective, and realized that by being prepared, she was no longer wasting her energy worrying about dying or resisting her situation.

The true peace of living with metastasis, I think, is to finally look death in the eye, accept it and move beyond the acceptance that breast cancer eventually will claim your earthly existence. I know that not everybody with metastasis would agree with this, but (I) find that many of us have found a great deal of peace in taking care of final details and making sure our affairs are in order. This is not to say that we've given up. I think my oncologist put it very well when he said that these things need to be in order so you don't worry about them and then can concentrate on letting treatments work and delay the inevitable.

For months after my metastasis diagnosis, I railed against doing such things. Yet every time I would get sick or have a bad bout, I would worry if this was going to be the beginning of the end or what. And nothing was taken care of. What would

happen to my kids? What about my husband, who would help him?

Finally, I decided (for once) to follow my oncologists advice and do it. My health care proxy, Living will and Last Will and Testament are taken care of. My instructions for funeral arrangements are written and a copy given to my minister, along with a final message from me to those who will mourn me. I've talked to my closest friends to make sure that they will be there for my girls and for (my husband)

As hard as it was to do these things, I found they also gave me a great deal of peace, even now as I don't have anything in particular to worry about. Of course, I do still wonder when the shoe will drop again. This damned thing must be a radiated octopus, it has so many shoes to drop. But while I wait, I live as best I can, enjoy my children and the other people in my life, without worrying about taking care of necessary details with regard to the end of my life. Facing the inevitability of death has set me free to live. It's very much the difference between living breast cancer and living with it (Anne).

Anne's reference to the difference between living breast cancer, and living with it, gives insight into the management of chronic illness. She expresses a fierce desire to carry on life as normally as possible. By dealing with the prospect of dying, she was able to prevent breast cancer from defining her life, and achieve a sense of control.

Women whose family members at least acknowledge the severity of their condition appear to be the ones best able to negotiate the tension between the present and the future, and prepare for the end of their life. Anne contributed to a thread on suicide, and told of her feelings on the subject.

I confess to being one of those with a cache of pills that continues to grow as my disease progresses. It seems to be stable now, as does the pill cache, and I am nowhere near the point that I would consider ending my own life. My family, and that includes my husband and four children aged 9-18, are aware that I do not want them to see me debilitated to the point that I cannot communicate with them, simply lingering in the shell of a body indefinitely. I watched this happen to my own mother many years ago and it is a memory I do not care to pass on to the next generation. My mother had no peace at her death, only suffering and a feeling of loss. My initial reaction-- as a 12 year old-- was one of release for both of us. Release for my mother from the incapacitated body that had withered and betrayed her in the last nine months of life; and release for me from the nightly trips to the hospital to watch her grown worse, day by day, long after I thought it

could get no worse. Eventually, I did mourn the loss of my mother, but it was a very long time in coming because the sense of relief was so pervasive. This is an individual choice, I believe, and not one to be dictated by anything other than one's own mores. I would not force my decision on another, nor will I have it forced on me by another. Though should I die by my own hand, I will not leave behind a shocked and confused family. They will know when and why, and hopefully, will be there with me to make the passing that much easier" (Anne)

Anne's wish is not to suffer as her mother did, and hence not to leave her family with painful memories of her passing. Her feelings are in keeping with the euthanasia and death-with-dignity movements (Kubler-Ross, 1969). She also portrays it as an individual decision, one that one took with the support of family.

### *Conclusion*

Discussion of death on the list often comes in peripherally, through discussions of treatment or family. List members talk about how best to prepare themselves and their loved ones. It is clear from the postings that when illness becomes serious and life-threatening women adjust to a new outlook on life and the future, one that maximizes enjoyment of good days. Control at the end of life means being able to make choices, such as not treating metastases until they become symptomatic, or stashing pills so that they will have the option of ending their own life if that is what they want at a later date.

For some dying is an opportunity for self-realization, or may bring a new awakening of spirituality. Women on the list have written about doing things, like travelling or artistic work, that they might not have otherwise discovered. They also talk about having a heightened appreciation for small, everyday things. Long term plans will become less important, and emphasis shifts to the present. By living in the present they are able to continue to enjoy life, and create happy memories for their family.

## Chapter Six

### Conclusion: The Breast Cancer Journey

The breast cancer list is frequented by women with breast cancer, their families and friends, researchers, and health professionals. Of the women who subscribe to this list the majority are *lurkers*, and only read what is posted there without writing anything themselves. Those who do post regularly are a smaller proportion of the list membership. This thesis has used posts written to the breast cancer list by women living with breast cancer, for a qualitative sociological analysis of their *illness narratives*; narrative type descriptions of life with this illness. Access to personal accounts by women actively coping with different stages of breast cancer enables an analysis of women's own perceptions of their illness.

Theoretical approaches to illness experience and illness narratives emphasise transition, changing sense of self, and the construction of a new life story. Reissman (1993) notes, in reference to narrative analysis, that text is not autonomous of its context. I have addressed three perspectives on breast cancer, all of which inform the narratives I have explored; cultural, medical, and psychosocial adjustment.

Most women have some exposure to our larger cultural understanding of breast cancer, shaped particularly by the media. In the media metaphors like "fight" and "battle" are part of how we understand the disease. Those with cancer are identified as either "victims" or "heroes", marking them as different either way (Sontag, 1978; Lupton, 1994). The media link breast cancer specifically to lifestyle choices, strongly implicating gender issues like diet and reproduction (Yadlon, 1997). The influence of

cultural meanings was especially evident on the list in the language that women used to describe their cancer and cancer treatment. Their perceptions of their social interactions in relation to their cancer, with family and friends, also implied that stereotyped views of breast cancer, illness and recovery were involved.

Second, those diagnosed with breast cancer are intensively exposed to medical understandings about the disease. Health professionals diagnose breast cancer, and describes it in pathological terms that these women themselves adopt. It presents women with treatment options to choose from, all with risks and benefits that must be weighed in making a decision. Furthermore health professionals promote informed decision-making much more now than in the past (Charles et al., 1998). Information seeking is also promoted by the list as a strategy for coping with breast cancer.

Women are probably less directly exposed to psychosocial research, which identifies the areas in which women with breast cancer have to make adjustments to cope emotionally and mentally. Through support groups and self help literature list members may learn about the issues addressed by this perspective. It examines persistent problems and the process of recovery, and compares psychosocial issues of women with breast cancer to those of peers without breast cancer, to assess its impact. The themes on the breast cancer list strongly reflect psychosocial issues prominent in this literature.

#### *Writing the Breast Cancer Journey*

The metaphor of breast cancer as a personal journey is often repeated on the list, and captures the meaning of the illness for these women. It conveys a sense that breast cancer is a defining moment, separating before and after. Breast cancer is experienced as

a chronic, rather than an acute illness, with long recovery periods and life long uncertainty. Thus, it has the potential to affect all aspects of a woman's life.

The period after surgery brings difficult decisions about adjuvant therapies, followed by treatment that may go on for months or even years. While other research has focused on decision-making styles or the degree to which women wish to be involved in making decisions about treatment (Hack et al., 1994), I have focused on how their experience of their illness and medicine results in different interpretations of and responses to adjuvant treatment. Three distinct types of narrative emerged from the list. First, for those who are overwhelmed by side effects, treatment means sickness and illness. Second, for those who talk mainly about their concern for the future, cancer treatment represents, as it often does in the media, a hard fight against disease. Finally, those who use palliative treatments are not fighting for a cure, and experience side effects as part of the alleviation of cancer symptoms. In two of these contexts it was evident that, as other research has found, doing something was better than doing nothing, even if the potential benefit was small (Charles et al., 1998).

Uncertainty and disruption are experienced daily by women with breast cancer, and this frequently emerges on the breast cancer list. These issues are associated with loss of self-identity, interference by medical appointments in their daily life, and time lost recovering from treatment. They are also experienced as uncertainty about the future, inability to make plans, never knowing what may lie ahead, and "waiting for the other shoe to drop." Normal life has to be re-negotiated in order to accommodate periods of sickness, check-ups, and long term problems due to cancer and cancer treatment.

Women on the list who were coping with advanced breast cancer had developed a different perspective on time from the others. The present became much more important, as did daily life, while long term planning was no longer as important to them. Posts by these women, perhaps more than the others, conveyed a balanced view of cancer, in terms of the positive changes it had brought to their lives, in addition to negative ones. Women at this stage conveyed an enjoyment of life, even gratitude, which was very much a part of their realization of their own mortality.

Some themes emerge from the narratives that provide interesting contrasts to previous research. For example, existing literature on breast cancer has identified survival as a distinct phase of the illness experience (Ferrans, 1994). Qualitative work in this area has developed around uncertain health, fear of recurrence, and long term side effects of cancer treatment such as lymphedema or premature menopause and infertility (Ferrans, 1994). An interesting issue that emerged from the narratives that I haven't found in qualitative literature about breast cancer, are women's complaints of cognitive dysfunction years after chemotherapy, and the problems it causes them at work. In the narratives I used here, this was associated with a "loss of self" (Charmaz, 1982).

Another interesting contrast to the existing literature was the theme of control over information by women with advanced breast cancer. Other research has linked information seeking and decision making, for example, and has found that information is a basis for an active approach (Charles et al., 1998; Hack et al., 1994). I found however that some women on the list with advanced cancer discussed limiting their knowledge of their disease. Opting not to monitor the spread of metastasis until symptoms appeared

was a choice they made to allow themselves to maintain some sense of normal life and wellness.

### *The Internet and Support*

From a research perspective, the narratives on the list are a source of rich sociological data. They offer unique glimpses and access into the complexities of life with breast cancer. Some of the material I found on the breast cancer list was very painful to read and difficult to approach in an analytical way (Cannon, 1989). At the same time, I felt fortunate to have discovered a place where women write so candidly about different aspects of their illness, and how it has affected them.

The stated purpose of the list from the perspective of its members is to provide a source of information and support. References to seeking and giving support are woven throughout the narratives I have used here. Because these list members write about their illness, other members have more than just literature and what their doctor tells them to help them understand their own illness and make choices. By sharing their experiences these narrative posters provide examples of what women actually do, or how they feel, when faced with breast cancer. Active members work to create a list that is what they wish it to be; a place to communicate and commiserate, to connect with those in similar situations and bear witness to the suffering of others, to offer and receive support. Spam and solicitous messages from outsiders are discouraged here. Members frequently refer to the list as a unique and special place.

The fact that the list is on the Internet is not incidental to its potential as a source of support. Computer-mediated interaction is unique in that it has both private and public

qualities. Participants have access to a large group, but exchanges are often characterized by intimacy (Lee, 1996). There are so many list members that on any given day at any time a member can log on to their e-mail account and likely find an ongoing exchange. This creates the feeling that the list is an actual place, one where there is a continuous flow of conversation and interaction.

Research has suggested the women with breast cancer who participate in psychosocial support groups may actually live longer, as well as being better able to cope with their illness (Spiegel, 1989). The list adds a new dimension to the traditional support group. Where as some women may find it difficult to get to face-to-face support groups, the list is accessible to those with restricted mobility, and requires very little energy to read and contribute to the conversation. The members themselves characterize the list as different from other types of support. "I am so glad to have this as my support group, there on an as needed basis rather than a weekly meeting. There really can be no substitute!" (Toby).

#### *Doing Social Research on the Internet*

In the course of my research I encountered three types of social research that take place on the Internet. The first is a modified version of traditional research, in that it simply uses the Internet as a means of accessing respondents for research instruments such as questionnaires and surveys. In these cases, the only challenge that the Internet poses is that respondents and researcher are geographically remote, and the researcher must adapt the research instrument and consent forms to the electronic medium. These types of researchers appear on the breast cancer list regularly.

My project was another type of Internet research, one that investigates on-line culture, or an issue in the context of an on-line forum (Sharf, 1997). This research takes the medium and Internet culture as part of the area of research. Some members have expressed some weariness or even hostility toward researchers of the first type, who solicit respondents, or post questionnaires that ask members to rate their experiences. I found that the women I asked to quote generally responded very well. Several thanked me for asking them to be part of my research, and nearly all took the opportunity to comment on their previous posts, or update me on their situation. Some of these women stated directly that they are more sympathetic to qualitative research because they feel it better reflects their experience as individuals. I also sensed that research that recognizes the list as a special group, rather than just a source of respondents, gets a better reception.

The third type of social research on the Internet occurs when constituents of groups like this one research and write about the forums that they participate in. Social scientists and writers who participate in forums, newsgroups and lists such as the breast cancer list come to see their research potential. Some breast cancer list members have written about their experiences and interactions there (Mayer, 1997). Their research involves reflecting on their own place in the group, and bringing social analysis to their personal experience.

Using the Internet for social research presents some difficult ethical questions that have yet to be answered, because the area is still relatively new. The private/public nature of the Internet poses a challenge for researchers. Participants on the Internet are generally aware that their words can be accessed by anyone. However, the immediacy of the medium and the personal nature of exchanges there mean that inevitably, participants

end up addressing members of the group as if it were a private conversation (Baym, 1995). Documents taken from an e-mail list or archive may be considered personal correspondence by some, and published documents by others (Till, 1997).

### *Strengths and Limitations of this Research*

Women who write to the list about their illness often disclose what they are feeling or experiencing at specific moments in time. This affords knowledge grounded in their perspective, to an extent that even the most sensitive, in-depth interviews might never achieve. However, little is known about these women besides what they chose to write. Returning to Reissman's discussion of validity in narrative (1993), it is difficult to know what alternative readings on these narratives might be, without more knowledge of the women who wrote them. I have looked at these writings in the context of the forum in which they were produced, and in light of themes that emerged there. Therefore my readings are plausible and coherent within this context. My interpretation fits the material I have used, and builds on these women's own understanding of their illness, while analyzing across narratives. However, these texts remain open to other readings.

Another indication of the plausibility of the reading of these narratives is to examine the extent to which they are in keeping with other work around living with breast cancer. My findings are similar to those in other qualitative research (Clarke, 1985; Coward, 1990; Ferrell, 1997, 1998; Pelusi, 1997). As in the psychosocial literature reviewed here, narratives from the list indicate that breast cancer affects all aspects of a woman's well being and quality of life; the physical, psychological, social and spiritual

(Ferrell, 1997, 1998). The list also clearly shows women experience different challenges at various stages of their illness (Ferrans, 1994).

Throughout, this has been a work of interpretive sociology. I have used narrative-type posts to the list to find out what breast cancer means to these women, how it has disrupted their normal lives and challenged their sense of who they are. This work carries with it the advantages and constraints of qualitative work. First, this work did not begin with a hypothesis, nor does it aim to verify a social theory. By using a descriptive approach my aim was to develop themes as they emerged from the list. While this can produce new insights and questions, as I have noted above, this analysis is limited to the narratives on the list during the period of my research and cannot be generalized beyond these, although it may expand understanding of some issues.

Further, the object of analysis here is stories by select women with breast cancer rather than all women with breast cancer. Information about these women is limited, and issues of race, class, age and education are not addressed here. These have all been found to be important variables for understanding the experience of breast cancer. Ganz (1998) found that socioeconomic status was a predictor of better psychological adjustment one year after diagnosis. Age is also an important variable in adjustment (Cameron, 1998). Other research has found that race is an important variable in breast cancer survival. African American women are more likely to be diagnosed at a later stage of breast cancer, raising concerns that breast screening and breast cancer awareness have not reached African American women effectively (Phillips et al., 1999). Quality of life research on African American and white women found that ethnic differences were in fact due to other factors, that ethnicity was a proxy for socioeconomic status, life stress,

living situation and comorbidity (Ashing-Giwa, 1999). Narratives that present these differences may not be present on the breast cancer list, due to its self selected membership.

### *Future Research*

Kleinman (1988) has said that illness can only be understood in the context of a life lived. The value of the list is that it provides access to women's own understanding of their situation and what they choose to tell about it. A follow up to this exploratory work could be the triangulation of methods to improve the reliability and generalizability of research based on issues that have been raised here, while still using women's own words to describe their experience. Surveys of list members in addition to using their posts would round out the data here, by providing demographic information.

It would also be useful to follow the posts of individual women from the time that they join the list, throughout the various stages of their illness. The collected posts of any of the women I have quoted here would provide valuable data, as they would tell the story of breast cancer from one individual's perspective. My time on the list was too limited to pursue such a project, but this is a direction that research on the breast cancer list or other health related forums could take in the future.

Social support is a prominent aspect of the list, one that could be examined more closely. The posts here emerge in the context of conversation, and it would be useful to understand more about the different types of exchanges and how they act as a source of support. Given that there are yearly meetings organized for list members and many informal meetings at other times, it would also be possible to observe how list members

interact when they meet face-to-face. This would be something to pursue in relation to the question of how face-to-face and online support compare.

As the number of people using the Internet and e-mail increases, computer-mediated communication has the potential to become an important source of support for those with illnesses, particularly those who may not have access to face-to-face support (Curran and Church, 1998). As the Internet becomes more accessible, it will no doubt be promoted as an important resource for women with breast cancer and other illnesses. As I have shown here, it is also emerging as an important site for social research.

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# Appendices

## Appendix A

### BREAST-CANCER Listserv

#### 1) Mandate and Purpose

An open discussion list for any issue relating to breast cancer. This is an unmoderated list open to researchers, physicians, patients, family, and friends of patients, for the discussion of any issue relating to breast cancer.

While some of the list will be devoted to discussions of medical advances, as well as possible therapeutic treatments, both mainstream and alternative, the list should also have a less rigorous side to it. The list does not recommend particular therapies, but seeks to increase the information available on options and choices.

It will also be a forum for breast cancer patients and their loved ones to vent frustrations and offer alternative strategies in dealing with the patriarchal medical-industrial complex, and to offer help and insights into the psychosocial management of the disease.

Finally, the list will offer a venue for the discussion of the work of various grassroots breast cancer advocacy groups world wide, to announce events, to exchange ideas related to breast cancer activism, and, more broadly, to discuss the politics of breast cancer and health care.

**PLEASE NOTE:** Increased public awareness of the role of BCRA1 and BCRA2 mutations in the etiology of some breast cancers has led to more people requesting and obtaining genetic testing for such mutations. If you have obtained such tests, **DO NOT POST RESULTS** to the BREAST-CANCER List!! The BREAST-CANCER List is widely distributed and postings are archived at a number of publicly accessible WWW sites. Genetic testing results are **HIGHLY CONFIDENTIAL** and dissemination of results may affect ones ability to obtain treatments and insurance benefits.

#### 2) How-to Post and Other BREAST-CANCER Commands

Please save this message for future reference, especially if you are not familiar with LISTSERV. This might look like a waste of disk space now, but in 6 months you will be glad you saved this information when you realize that you cannot remember what are the lists you are subscribed to, or what is the command to leave the list to avoid filling up your mailbox while you are on vacations. In fact, you might create a new mail folder for subscription confirmation messages like this one, and for the "welcome messages" from the list owners that you will occasionally receive after subscribing to a new list.

**POSTING TO THE LIST:** To send a message to all the people currently subscribed to the list, just send mail to [BREAST-CANCER@morgan.ucs.mun.ca](mailto:BREAST-CANCER@morgan.ucs.mun.ca). This is called "sending mail to the list", because you send mail to a single address and LISTSERV makes copies for all the people who have subscribed. This address ([BREAST-CANCER@morgan.ucs.mun.ca](mailto:BREAST-CANCER@morgan.ucs.mun.ca)) is also called the "list address". You must never try to send any command to that address, as it would be distributed to all the people who have subscribed. All commands must be sent to the "LISTSERV address", [LISTSERV@morgan.ucs.mun.ca](mailto:LISTSERV@morgan.ucs.mun.ca). It is very important to understand the difference between the two, but fortunately it is not complicated. The LISTSERV address is like a FAX number, and the list address is like a normal phone line. If you make your FAX call someone's regular phone number by mistake, it will be an unpleasant experience for her but you will probably be excused the first time. If you do it regularly, however, she will probably get upset and send you a nasty complaint. It is the same with mailing lists, with the difference that you are calling hundreds or thousands of people at the same time, so a lot more people get annoyed if you use the wrong number.

To prevent unsolicited distribution of large binary files, email file attachments and to facilitate reading the BREAST-CANCER List when it is received in DIGEST form (see below), line limitations have been imposed. Global restrictions @morgan limit email messages to 2 MB or less; size limitations of 1000 lines or less are in place specifically on the BREAST-CANCER List. If you attempt to send a message that exceeds these limits, it will be rejected.

At the present time, there are about 700 people from more than 30 countries subscribed to the BREAST-CANCER List. This translates to at least 100 postings daily. The server software provides a posting daily limit to protect the email community-at-large from situations where automatic mailings-gone-mad could occur. The default setting is 50 mail messages per day. Currently, given the size of this community and traffic, this default setting has been increased to 150 postings per 24 h. If traffic exceeds 150 posts in any one day, further BREAST-CANCER traffic is halted until myself or my sysops examine the situation and restart the server. Among many various solutions available, list traffic can be kept to a reasonable and manageable level if users remember to group messages

addressing various subscribers or threads on the List under a single mail heading, and to personally email fellow subscribers \*off-list\* whenever possible or appropriate.

To reduce software and hardware strain accompanying the volume of messages handled daily by the BREAST-CANCER Listserv, the following measures are currently in place to reduce error message traffic: 1) Auto-delete functions of LSoft listserv software have been made more stringent: Any address that generates 50 error messages in total, or for a duration of 3 days, whichever comes first, will be DELETED from the B-C subscription list; 2) For many reasons, LSoft listserv software does not automatically recognize all address formats, and so cannot see all errors. But I can! From now on, any address reporting mailbox full (ATTN: AOL users especially!), transient failure, name server timeout, etc for 3 days, will be DELETED! Any address reporting unrecoverable error such that messages in a queue will be deleted, will be DELETED immediately from the B-C List subscription list. 3) Upon initial sign-on, as well as every 60 days subsequently, subscribers will be asked to confirm their request to sign on. This will reduce subscriptions from incorrect or bogus email addresses, and further reduce error messages. We are working to remove the confirmation requirement from the unsubscribe request - it is not clear how as it appears connected to my password protected functions. I'll be back to you concerning this.

4) Every 60 days Listserv will automatically ask all users set to NOMAIL if they wish to RENEW their subscriptions. You will have 7 days to reply to the message. If you do not, you will be automatically DELETED. If in the time you have been on NOMAIL your address has changed you may be unable to renew easily (see 3 above), but again it should keep the list leaner and more efficient.

If you find yourself signed off, please do not take offense. You have very likely not \*done\* anything for which this might be retribution. If you find yourself unceremoniously signed off without your knowledge, check that your mailbox is not full, and that your system is not down. If all is well, simply resubscribe.

**SUBJECT HEADINGS:** In order to allow efficient searching of digests and archives (see below), as well as to give recipients some idea as to the issues you wish to address in your posting, we suggest that you pay particular attention to the "Subject" line of all submissions. Rather than simply hitting the "Reply" function, please take a moment to double check the "Subject" heading and ensure the existing "Subject" remains true to your post.

**\*\*\*PLEASE NOTE\* LISTSERV does not compute messages containing a signature file (.sig file, like mine below). ALL MESSAGES DIRECTED TO LISTSERV@morgan MUST BE DEVOID OF .SIG FILES (I.E. SIGNATURE FILE FUNCTION "OFF")!\*\*\***

**DIGEST FORMAT:** By sending a SET BREAST-CANCER DIGEST command to [LISTSERV@morgan.ucs.mun.ca](mailto:LISTSERV@morgan.ucs.mun.ca), you can change your mechanism of receipt of postings- from individual, full-header messages received as they are sent to the List by subscribers, to a single (rather large) daily collection or "digest" of messages with condensed headers. This is particularly useful if you have limited mailbox space, pay per message received, or simply like to download mailings and search according to your particular interests. To revert to default settings (i.e., to receive individual postings), send a SET BREAST-CANCER NODIGEST message to [LISTSERV@morgan](mailto:LISTSERV@morgan).

**NOMAIL:** If you wish to temporarily halt the receipt to BREAST-CANCER postings, but remain subscribed, you can do so by sending a SET BREAST-CANCER NOMAIL command to [LISTSERV@morgan.ucs.mun.ca](mailto:LISTSERV@morgan.ucs.mun.ca). To return to receiving regular mail, send a SET BREAST-CANCER MAIL command to the same address. Remember, if you remain NOMAIL for 60 days or more, **LISTSERV** will ask you to RENEW your subscription (see #4 above).

**LEAVING THE LIST:** You may leave the list at any time by sending a SIGNOFF BREAST-CANCER command to [LISTSERV@morgan.ucs.mun.ca](mailto:LISTSERV@morgan.ucs.mun.ca). **\*\*PLEASE NOTE:** **LISTSERV** will then send you a message asking for a confirmation of your request to signoff. Please do not overlook this, because without it your request will be ignored\*\*. We are currently reviewing the need for this confirmation request upon unsubscription. Please stay tuned!

**ARCHIVES:** The BREAST-CANCER List has been continuously archived, since our inception, at nysernet's Breast Cancer Information Clearinghouse ([gopher://nysernet.org:70/11/bcic-archive](mailto:gopher://nysernet.org:70/11/bcic-archive)), and more recently at the Association for Cancer Online Resources (ACOR) homepage (<http://www.medinfo.org/listserv.html>). Both are searchable by keyword.

**OTHER OPTIONS:** You can also tell **LISTSERV** how you want it to confirm the receipt of messages you send to the list. If you do not trust the system, send a SET BREAST-CANCER REPRO command and **LISTSERV** will send you a copy of your own messages, so that you can see that the message was distributed and did not get damaged on the way. After a while you may find that this is getting annoying, especially if your mail program does not tell you that the message is from you when it informs you that new mail has arrived from BREAST-CANCER. If you send a SET BREAST-CANCER ACK NOREPRO command, **LISTSERV** will mail you a short acknowledgement instead, which will look different in your mailbox directory. With most mail programs you will know immediately that this is an acknowledgement you can read later. Finally, you can turn off acknowledgements completely with SET BREAST-CANCER NOACK NOREPRO.

If you have any further questions about the BREAST-CANCER list, write to the list owner, Jon Church, Faculty of Medicine, Memorial University of Newfoundland, at: [jchurch@morgan.ucs.mun.ca](mailto:jchurch@morgan.ucs.mun.ca) jon church memorial university of newfoundland st. john's, newfoundland (the eastern edge...)

### Request to Quote

My name is Katharine King. I am a Masters student in the Department of Sociology at Memorial University, St. John's, Newfoundland, Canada. I monitored the Breast Cancer List (Breast-cancer@morgan) from October 1997 through February 1998. I wish to use material that you have posted to the list during this period for my thesis research. My thesis will examine illness narrative by women with breast cancer. The aim of this study is to understand the everyday lived experience of women coping with breast cancer, from the patient's perspective. My thesis committee members include Dr. Barbara Neis and Dr. Marilyn Porter of the Department of Sociology at Memorial University, and Dr. Jon Church, of the Faculty of Medicine at Memorial University and administrator of the Breast Cancer Listserv. Upon request, the committee members' e-mail addresses, my thesis proposal, and the thesis itself can be provided.

Although the list is publicly available, I must have your consent before reproducing all or part of any of your messages in my thesis. Your consent is, of course, voluntary and you may withdraw it at any time prior to the completion of my thesis. I will not use your real name in my thesis. However, I cannot guarantee anonymity because quotes contained in my thesis could be traced to you using a key word search of the breast cancer archive.

A numbered list of the quotes I wish to make from your submissions to the list appears below. If you consent to the use of all of the above quotes in their present form, please insert your name in the paragraph below. You may be willing to approve the use of some of these quotes but not all of them. If you are willing to provide partial consent, please indicate the numbers for those quotes you authorize me to make below:

I (your name), give Katharine King permission to use the quotes specified here. I understand that my participation is voluntary and that I may withdraw at any time. Date:

If you would like to receive a copy of the thesis proposal and/or the thesis (in electronic format) please complete the following:

I wish to receive a copy of the thesis proposal: yes/no

I wish to receive a copy of the thesis once it has been completed, accepted by the School of Graduate Studies of Memorial University and released for public distribution: yes/no

Please note that the thesis will be protected by copyright and must be referenced if it is quoted.





