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LEARNING FROM WOMEN WITH BREAST CANCER:
AN ETHNOGRAPHIC STUDY

by

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A Dissertation Submitted in Partial Fulfillment of the
Requirements for the Degree of

DOCTOR OF PHILOSOPHY

in the Department of Psychological Foundations in Education

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Abstract

The purpose of this cross-sectional ethnography was to develop theory and knowledge about how women in Canada live with breast cancer. Cross-sectional ethnography describes a number of individuals from a cross-section of a culture or subculture for a unit of study (Boyle, 1994). A cross-section of women with breast cancer were studied, not an interacting group of women with breast cancer (Werner & Schoepfle, 1987). As a result of counselling women with breast cancer over a period of two years, I have learned that despite the differing treatment protocols and differing kinds and stages of breast cancer, women with breast cancer are members integrated into a subculture which has many common words, phrases, images, and themes. Thirteen women with breast cancer form the unit of study for this research. Cancer is a complex array of diseases which develop in 25% of the population; one woman in nine is diagnosed with breast cancer in Canada (Holland, 1989), and one woman in three with breast cancer will die of metastases (Elliott, Rahimi, Tremblay, Shenoy, Rossiter, & Saulnier, 1997). The incidence of breast cancer is increasing annually (O'Donnell, Coughlin, & LeMarbre, 1992); breast cancer is the most frequent cancer in women and is the leading cause of death in women between the ages of 35 and 55 (Andrulis, 1997). Secondary goals of this research were to have the emergent knowledge published to provide increased choices and actions for those newly diagnosed with breast cancer, and to provide data, facts and information to counsellors, professionals and others working and living with breast cancer. Psychological distress in women with breast cancer is often translated into

psychopathology by those following the medical model in breast cancer treatment (Mathieson, 1991). Depression and anxiety diagnoses are predominant in women with breast cancer, with rates of depression diagnoses as high as 75% (Massie & Holland, 1989). A study by Garcia, Cristal-Luna, Li, Uai, Gonzalez, Tarmayo, Masadao, Lola, and Matumog (1997) concluded that the presence of cancer disrupts almost every aspect of an individual's life and that depressive symptoms were experienced throughout the course of chemotherapy. Symptoms experienced by breast cancer patients are often translated by DSM IV criteria into psychiatric disorders, most often depression and anxiety (Derogatis, Abeloff, & Melisaratos, 1983). After counselling women in two cancer Clinics, I began to understand that the experience of having breast cancer imposes many stresses which are in fact, normal, given the context of the cultural stigmata and traumata which result from the diagnosis and treatment of this disease. Women caught up in the shock of diagnosis and the invasive treatments alluded to colloquially as "slash, burn, and poison" blamed themselves. Most of all they asked: "*How do other women live with breast cancer?*" This study is an initial response to that question.

Thirteen women who had been diagnosed with breast cancer participated in this study. A cross-sectional ethnography was the research method. Ethnographic questioning (Spradley, 1979) is used to organize and analyse data. Using the North American culture as background, and the subculture of those with breast cancer as foreground, ethnographic questioning elicited the shared contexts of 13 women's life worlds as they described their experiences after a diagnosis of breast cancer. This ethnographic method facilitated the analysis of the women's experiences by searching for cognitive and

behavioural themes of meaning in the women's verbal descriptions. Dominant themes which emerged and recurred through the 13 interviews were: 1) adaptation to ambiguity and stress; 2) sadness and anger; 3) fear and terror; 4) lack of support; 5) dehumanization; 6) disempowerment and trivialization; 7) shame and stigma; 8) coping; 9) minimization and denial; 10) it (cancer) changes everything; 11) the game of survival; 12) the doctor is God; and 13) metaphors, images, and other cultural symbols specific to those with a diagnosis of breast cancer. Conclusions recommend the inclusion of these and other themes in the psychotherapeutic frameworks utilized by those counselling individuals with a diagnosis of breast cancer.

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TABLE OF CONTENTS

ABSTRACT	ii
TABLE OF CONTENTS	vi
LIST OF FIGURES	xi
ACKNOWLEDGEMENTS	xiii
DEDICATION	xiv
CHAPTER 1: INTRODUCTION	1
The Culture of Cancer	2
Coping with Cancer	16
Cancerphobia	20
Cultural Messages about Women	23
Cultural Messages about Breasts	26
The Biomedical Model	29
Ethnographic Methods	32
The Rationale for the Study	38
CHAPTER 2: REVIEW OF THE LITERATURE	45
Literature: Cancer and Stress	45
Literature: Cancer and Coping	49
Literature: Theoretical	51
Literature: Family Members and Support Workers	53

Literature: Autobiographical Accounts	55
Literature: Case Studies	56
Literature: Surveys	57
Literature: Questionnaires	57
Literature: Other Research Methods	59
Literature: Phenomenological Studies	60
Literature: Denial	62
Literature: Personal Meaning	62
Literature: Counselling	64
Conclusion	68
CHAPTER 3: METHODOLOGY	71
Cross-sectional Ethnography and Ethnographic Questioning	71
The Research Process:	74
Inquiry	74
Finding the Women	75
Initial Contact and Entering the Field	77
Pilot Interview	78
Interviews with Informants	79
Sample Ethnographic Questions	79
Analysis	80
Assumptions of the Study	80

Limitations of the Study	82
Implications for Counsellors and Educators	83
CHAPTER 4: THE ETHNOGRAPHIC TEXT	84
The Women	85
Yolande	85
Sharon	87
Elaine Zyri	90
Carol	93
Donna	96
Laura	99
Rose	102
Vera	104
Anne Marie	108
Margaret	111
Denise Forest	114
Jane	117
Susan Harris	121
CHAPTER 5: ETHNOGRAPHIC ANALYSIS	126
Descriptive Questions	127
Structural Questions	130

Contrast Questions	132
Domain Analysis	135
Taxonomic Analysis	136
Componential Analysis	137
Theme Analysis	138
CHAPTER 6: DISCUSSION AND CONCLUSION	172
Implications for Counsellors and Counsellor Training Programs	177
Breast Cancer Counselling Guidelines	180
1. Ambiguity and Stress	180
2. Dehumanization	180
3. Disempowerment and Trivialization	181
4. Shame and Stigma	181
5. Coping	182
6. Minimizing and Denial	182
7. It Changes Everything	183
8. The Game of Survival	183
9. Doctor is God	183
10. Sadness and Anger	184
11. Fear and Terror	184
12. Lack of Support	185
Conclusion and Further Direction for Research	185

REFERENCES 187

APPENDICES 208

 A. British Columbia Cancer Agency Envelope (BCCA) 208

 B. Advertisement for Subjects 209

 C. Letter of Consent 210

 D. Glossary of Terms 212

 E. Universal Semantic Relationships 223

 F. Demographics 224

LIST OF FIGURES

1. Domain Analysis Worksheet: Elaine Zyri	141
2. Domain Analysis Worksheet: Laura	145
3. Making a Taxonomic Analysis	147
4. Taxonomic Analysis—Example	148
5. Taxonomic Analysis of Loss: Yolande	149
6. Taxonomy of a Part of Feeling My Whole World had Crashed: Denise Forest	150
7. Step in Componential Analysis: Denise Forest	151
8. Paradigm Worksheet: Jane	152
9. Discovering Cultural Themes: Ambiguity/Stress: Anne Marie	153
10. Discovering Cultural Themes: Dehumanization: Sharon	154
11. Discovering Cultural Themes: Disempowerment/Trivialization: Susan Harris ...	155
12. Discovering Cultural Themes: Shame/Stigma: Carol	156
13. Discovering Cultural Themes: Coping: Vera	157
14. Discovering Cultural Themes: Minimizing/Denial	158
15. Discovering Cultural Themes: It Changes Everything: Laura	159
16. Discovering Cultural Themes: The Game of Survival: Margaret	160
17. Discovering Cultural Themes: Doctor is God: Rose	161
18. Discovering Cultural Themes: Metaphors/Images of 12 Informants	162
19. Major Recurrent Themes: Adaptation to Ambiguity/Stress	168
20. Major Recurrent Themes: Sadness/Anger	169

21. Major Recurrent Themes: Fear and Terror 170

22. Major Recurrent Themes: Lack of Support 171

ACKNOWLEDGEMENTS

I wish to acknowledge the assistance of the many individuals who supported me:

My clinical supervisors, Professor Vance Peavy and Professor Don Knowles of the University of Victoria, and Michael Boyle of the Victoria Branch of the B.C. Cancer Clinic, who helped me to launch, develop, and complete this research;

The many women who responded to the call for research informants and the 13 women who participated in the study and so generously shared their experiences;

My supervisor, Dr. R. Vance Peavy, who supported the value of this research;

My committee members~Dr. Jennifer Hill, Dr. Mary Ellen Purkis, and Dr. Anne Marshall for their encouragement and valuable feedback;

My daughters, Lisa, Jenna, and Catherine, who supported me and believed in me with endless love through all the ups and downs, and who affirmed in me the belief that I could do anything I wanted;

My sister Linda and my mother-in-law, Mary Hastings, who have always supported me;

My colleagues and friends and community members of Canim Lake Band;

My colleagues, Shanti Persaud, Lynda Miller, Irena Bevc and Lona McRae, for your help; and a particular thank you to Margot Louis.

My mentors, Doctors Kathy Belicki, Sandra Pyke, and Kazimiera Stypka for your absolute trust and steady support and encouragement;

A special thank you to Lisa for your many hours and days of library help;

A special thank you to Jenna for your many, many hours of detailed editing; and

A special thank you to Kevin for your creative assistance with the figures.

DEDICATION

For

Patrick, Kira and Owen

And

Michael

For your patience and understanding.

CHAPTER 1: INTRODUCTION

The major focus of this study is an examination of what it is like to live in the North American cultural context with an experience of a diagnosis of breast cancer.

Cross-sectional ethnography is the research design. Ethnography describes the language and behavioural aspects of a culture or subculture. Ethnography also includes various artifacts of the culture under study such as poetry, literature, and literature review of the topic. All these components will inform this study. Werner and Schoepfle (1987) describe four categories of ethnographies. These are:

- 1) classical or holistic ethnography;
- 2) particularistic or focussed ethnography;
- 3) cross-sectional ethnography; and
- 4) ethnohistorical ethnography.

Classical or holistic ethnography is considered by anthropologists to be a description of a whole cultural system. Health would be described, if at all, in a subcategory. Particularistic (or Focussed Ethnography in Nursing), is the employment of the holistic approach to describe a small group of people (minimum 5) within a given topic (Morse, 1992). Cross-sectional ethnography is one in which a cross-section of a specific group is described using data collected from a cross-section of individuals from that particular group. Ethnohistorical ethnographies describe cultures of the past using the present tense.

A cross-sectional ethnography research method was chosen, one which includes a literature review, to fulfill the requirements of this research for investigating a specific subgroup in our North American culture: women with a diagnosis of breast cancer. In this

study, “the focus is on a group of people who share similar cultural characteristics” (Boyle, 1994, p.170). Instead of relying on key informants who assist the researcher with data collection and interpretation, I wanted to interview individuals across as wide a spectrum of breast cancer and social backgrounds as possible to see what patterns and themes emerged. I wanted to do an ethnographic analysis of informants’ language in order to search out patterns and themes in breast cancer clients’ lives, so as to produce theory which would inform and teach others about this experience.

Bernard, a cultural anthropologist, stated:

The word “analysis” has two meanings. On the one hand, it means making complicated things understandable by reducing them to their component parts. This is descriptive analysis. On the other hand, it means making complicated things understandable by showing how their component parts fit together. This is theory (Bernard, 1988, p. 317).

Using this ethnographic method of analysis, I, the researcher, use the informants’ descriptions to show how “the component parts” of their experiences result in a counselling tool to guide others. Further discussion of ethnography will follow later in this chapter and later in Chapter 3. Next, I review and describe the major aspects and dimensions of this study. I begin with some illustrations of the culture of cancer in our North American culture.

The Culture of Cancer

Cancer is a group of over 200 different diseases which develop in 25% of the population (Monat & Lazarus, 1991). A diagnosis of cancer, wherever the site, is perceived by some in our white western culture as a death sentence (Gerits, & De Brabander, 1997; Sontag, 1978). In the early 1900s, cancer accounted for 5% of

American deaths. Twelve percent of adult women in the United States will develop breast cancer; 3.5% will die from it, and though overall death rates from breast cancer appear to be stable, age group analysis shows that mortality is decreasing in younger women and increasing in older women (Harris, Lippman, Veronesi, & Willett, 1992). Presently, in 1997, cancer accounts for 24% of deaths and it is anticipated that it will soon overtake heart disease and become the leading cause of death (Brady, 1997).

In North America, Batt (1994) reported that every four minutes a woman is diagnosed with breast cancer and that every 12 minutes a woman dies of breast cancer. Other statistics (Holland, 1989; O'Donnell, Coughlin, & LeMarbre, 1992) indicate that one in nine women in Canada will receive a diagnosis of breast cancer. Moreover, there has been no noticeable change in the mortality of those with a diagnosis of breast cancer since 1930 when the recording of statistics of breast cancer began in North America. Most women will be silent about their experience, precisely because it is upsetting to others. As Jane, an informant who is also a physician, states:

You're upset, already, you've got to start being strong for everybody else, your kids . . . It's important . . . Because I care about them, I can't just put myself first.

The incidence of breast cancer has been increasing steadily and frighteningly over the past 40 years in America and many other countries. There are a number of known risk factors which include the following: breast cancer in mother or sister; age (i.e., age at the onset of menstruation, at first pregnancy, at full term delivery, and at menopause); number of children; total duration of breast feeding; exposure to endogenous and exogenous oestrogens; exposure to radiation; country of origin; and diet. These factors

account for only one third of breast cancer cases. Risk due to heredity accounts for approximately five percent of diagnosed breast cancer (Love, 1990). Many other factors are currently being investigated, such as psychological and environmental factors (Gilka, 1997).

In my experience, the most dreaded illness in our culture is cancer. Essayist Susan Sontag, after her own experience of remission from a gravely serious breast cancer diagnosis and its subsequent treatment, explored the cultural issues surrounding cancer in her essay entitled *Illness as Metaphor* (1978). She begins by speaking generally about illness, then more specifically about cancer. Such is the imperative of silence with regard to having cancer that she clearly states that she is not writing describing her experience, she is writing only about metaphor:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

I want to describe, *not what it is really like to emigrate to the kingdom of the ill and live there*, but the punitive or sentimental fantasies concocted about that situation: *not real geography*, but stereotypes . . .

My point is that illness is *not* a metaphor . . . Yet it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped (pp. 3-4).

For all the progress in treating cancer, many people still subscribe to . . . cancer equals death (p. 19).

As Sontag so clearly illustrates, a stigma surrounds the word cancer in our culture.

Cancer. Death. For many people the words are synonymous. The smell, the stink of cancer. The terror of pain. Suffering. The smell of death. Mortality.

Not only does the word cancer evoke dread and terror because of the reality of the known pain, suffering, and death associated with the diagnosis, but also because of the taboo status accorded cancer. The elusive and mysterious nature of the unknown--why cancer happens when it does, and to whom it does--compounds the fear of illness. Cancer is bad news. Cancer is frightening. Cancer is often seen as a personal attack. Many, if not all, cancer clients feel victimized, and in our culture victims tend to be silenced. For example, when Jane, an informant who is a physician, shared her experience with breast cancer with a colleague, this is what happened:

I support her a lot, that's what I do, in my life. I think I support other people. It wasn't then, I think, that she said it. But sometime in the next two weeks, talking about the surgery, she said, she was trying to be understanding, but she said, something about, "Oh, but, of course, you're going to be deformed." Thank you, K.

The things that people say to you, you just feel like saying, "Just don't say it." If you have one thing to say to people, if you're not sure what to say, say you care, but keep those things to yourself, your own hangups. So now you know that person's no good to turn to, that's another one.

In our death-denying, illness-denying, and victim-blaming culture, cancer is frequently a private affair.

For an illustration of the respect accorded the private aspect of having cancer, one provincial cancer agency located in B.C. has only discreet initials on its envelopes and letterhead so that the privacy of cancer patients can be protected; only the enculturated

can decipher the initials BCCA (British Columbia Cancer Agency, see Appendix A).

Many individuals with a diagnosis of cancer do not want others to know. The taboo and stigma are so powerful that, still, today, family members actually may ask that a doctor not disclose the diagnosis of cancer to a patient. Sontag states:

Cancer patients are (often) lied to, not just because the disease is (or is thought to be) a death sentence, but because it is felt to be obscene--in the original meaning of that word: ill-omened, abominable, repugnant to the senses. Cardiac disease implies a weakness, trouble, failure that is mechanical; there is no disgrace, nothing of the taboo that . . . still surrounds those who have cancer. The metaphors attached . . . to cancer imply living processes of a particularly resonant and horrid kind (p. 9).

She continues:

Patients who are instructed that they have, unwittingly, caused their disease are also being made to feel that they have deserved it. Punitive notions of disease have a long history, and such notions are particularly active with cancer. There is the “fight” or “crusade” against cancer; cancer is the “killer” disease; people who have cancer are “cancer victims.” Ostensibly, the illness is the culprit. But it is also the cancer patient who is made culpable. Widely believed psychological theories of disease assign to the luckless ill the ultimate responsibility both for falling ill and for getting well. And conventions of treating cancer as no mere disease, *but a demonic enemy make cancer not just a lethal disease, but a shameful one* (Sontag, 1978, p. 57).

Although Sontag wrote this years ago, her words apply aptly today. Little has changed. In my experience of counselling those who have had a diagnosis of cancer, both at B.C. Cancer Clinics in Victoria and Vancouver, and at the Princess Margaret Regional Cancer Hospital in Toronto, the stigma and taboo of having a diagnosis of cancer are alive and flourishing.

In both group and individual sessions, cancer clients disclose their own sense of being stigmatized by friends and family. As one client said,

They mean to be supportive, but . . . They don't know what to say. I don't know what to say, either. I end up taking care of them, ignoring what's going on for me, pretending I'm all right. A very dear close friend found she could not take a sip of water out of a glass which I had drunk from, a practice we normally shared. I was devastated. She obviously believed the cancer might be transferred to her. I felt contaminated, not fit to be around others. (Personal communication, N., a breast cancer survivor, August, 1995).

Jane, an informant, states:

The worst thing, for me is dealing with other people, because when you're there, . . . I met the internist from W., who was skiing with his wife, and they came in for lunch. They've stayed at our house, and I've had a bit to do with them through work and through this medical society we used to have here. He's an older guy, probably 10 or 15 years older than me, and he was there. He always seems quite friendly, smiles quite a lot, and he says, "Oh, how are you?" And I thought, "Yikes, does he know? I guess he doesn't know, what am I going to say?" He's going to think, that's weird if she doesn't say anything when he hears later. So I said, "Oh, well, it's not been one of my better weeks."

And I thought, if he does know, he'll pick up on that, that it's all right to say something, because I had to think quickly. And he said, "Oh" and left it. So I'm left hanging. And that's how I felt exactly. I guess he doesn't know. So I stepped over so I was closer to P. than to R., and I said, "I guess you haven't heard that I just was diagnosed with breast cancer." And he said, still smiling, "Oh, yes, J. told us." And I wanted to say, "Then why didn't you say something? Don't drag it out of me. Don't make me have to say it." Every time I say it, it's like, you might next moment start screaming, you know? You're holding yourself together with it. What an idiot. He's a doctor, what an idiot! I was angry at the time. I guess you're angry at other things, too. But that's stupid behaviour, from someone who should know better. That hurt quite a bit.

So, on the weekend I phoned my parents-in-law because they hadn't called to talk to me. I said to B., "I'd better call them and let them know it's all right to talk about it." My father-in-law said, after I'd talked to him, "Well, you seem to be handling this very well." And I said, "Well, G., what else can I do?" But that set the tone for the next few months. They never sent flowers. They never remembered to call when I had my chemo. Always, I remembered to call them. None of B.'s family ever came up to us.

I was really hurt. It was worse than having cancer, it was worse. But you don't find out, you know, that people have trouble dealing with illness, 'til you have it. And they have big trouble dealing with cancer.

After a cancer diagnosis, many clients comb through their past as with a fine tooth comb, with anguish, looking for a cause, looking for something they did or experienced. Our culture has a vested interest in cause and effect, in the 'just world' hypothesis, that if I am good, bad things won't happen to me. If bad things do happen to me, folk wisdom suggests that I did something to deserve it. Without such a hypothesis, the reality that random acts can strike anyone at any time are too threatening to accept. Many clients take these ideas seriously. Many individuals I worked with assumed responsibility for 'getting cancer.' Jane states:

But it was the stress of the way that we got to stay (in that country). I had to really accept that what I had always wanted to do which was to return (to New Zealand). . . I was not going to get to do it. It was hard. I could see it. This is not healthy. I'll end up getting cancer or something. If stress has a role, I'll end up with something, this is not healthy. And that was even when I had the undiagnosed . . . which certainly wasn't helping, in retrospect, the way I felt. Anyway, that was my first reaction.

But I said, "I feel awful because I can't help feeling that I've done this to myself. That if I could have coped better, I wouldn't have got it (cancer)."

Some individuals describe themselves as victims. To them cancer is like a runaway car or violent attack; it has struck them randomly. Others describe themselves as deserving of the cancer diagnosis, or as bad persons, or as gangrenous. Many breast cancer clients describe experiencing an ineffable sense of wrongness, of being guilty, of being responsible, culpable. In my experience, there is no age, race, or gender difference in this need for attribution in order to explain the 'effect' of having cancer. There is often

guilt experienced by clients around such cultural notions about cancer and food, etc.

Sharon, an informant, states:

Although I must tell you something funny, I ate broccoli for years because it was said if you ate broccoli, you wouldn't get cancer. And once I was diagnosed with cancer, I immediately stopped eating broccoli. I always hated it, but I was eating it because it was good for me and I wouldn't get cancer.

And again, later in the interview:

. . . this business with broccoli. I grew it, and I could never could understand why it was considered healthy because when you grow it in your own garden, it's full of little green worms. The first time I cooked it, I wasn't aware of this, and all these little green worms came up in the water, and I thought, ooh, protein! But I'd better not tell my family about this, as I scooped the worms out and threw them in the garbage. And after that I learned to soak the broccoli in salt water before I cooked it. But I thought, the growers that are growing this broccoli which is advocated as being good for you, to prevent you from getting cancer, they have got to be spraying it with something to prevent the green worms, so how can this be good for you?

She also queried the popular idea that stress actually directly causes cancer;

They say you've already had cancer 8 to 10 years by the time it shows up on a mammogram. So if I go back that far, I don't know what stresses (there were) in the years 1983-1985 which I remembered as happy.

Receiving a diagnosis of cancer is an experience described as 'the worst possible scenario' by many clients. When they come for counselling, virtually all clients want to know more about how others live with or cope with this situation. They want education as well as counselling. Referring clients for group therapy addresses this need only in a limited way since the emphasis in groups, at group members' requests, is often on learning specific skills such as Visualization Techniques or Relaxation Training. The taboo against and stigma regarding speaking about one's cancer is very powerful. A research report for those who work with educating and counselling cancer clients and

their families will have an impact in reducing both stigma and taboo. This will result in improved psychological health for clients.

Women who are currently living with a diagnosis of breast cancer often find that their daily functioning in the world is profoundly affected, particularly in their perceived loss of control and quality of life (Alastair Cunningham, personal communication, May, 1995). As they adjust to a potentially chronic, life-threatening illness, many want to know more about how other similarly diagnosed women cope. They also ask about women whose breast cancer is in remission and how they have lived their lives. The women want to hear from others who have 'been there.' Women with breast cancer state they are upset, confused, and frightened by the medical information available to them. They tend to find that present medical research concentrates on a search for the cure for breast cancer by looking at basic cell biology and by testing horrific drug 'cocktails,' not by investigating environmental effects (Benston, 1989). The heroic breast cancer treatments of surgery, radiation, and chemotherapy referred to by breast surgeon Dr. Susan Love, as 'slash, burn, and poison' create major physical manifestations of illness (Love, 1990). A doctor (anonymous) was quoted by Sharon Batt in Patient No More: The Politics of Breast Cancer (1994):

With chemotherapy and cancer, we're at about the same place we were when we used to treat syphilis with arsenic. It if doesn't kill you, it can help you (p. 90).

In response to clients' questions when counselling those with breast cancer during my Internship at the B.C. Cancer Agency in Victoria, I looked for research about breast cancer patients' experiences of living with breast cancer. I found no studies of those with

breast cancer which explored, with some scientific rigour, from the insider's point of view, how women live with such contingencies of breast cancer as the side effects of surgery, treatment(s), daily pain, family and work roles, issues of family care giving, and interactions with the medical profession.

What are the experiences of women living with breast cancer? That question is the basis for this ethnography. When I was counselling women who had been diagnosed with breast cancer, I heard similar questions over and over again. Each person had her own unique experiences, yet there were parallels and congruencies amongst the stories. Over time, I became aware that women had behaviours and thoughts in common, and that there were specific linguistic phrases and words which recurred across the accounts. For example, frequently, it appeared that cultural interactional factors challenged an individual's identity and concept of herself as a healthy person. The reconceptualization of self as a 'sick person,' one who not only had cancer, a disease of death, but also had breast cancer, a perceived attack on femininity, often led to self-blame for the illness. When women with breast cancer come to counselling, many start by asking how other women in a similar situation cope. One problem for the counsellor and client is the paucity of non-biomedical information in the research literature. Clients want information and education as well as counselling. Yet the only pamphlets available are in the medical model and are often ambiguous in both content and medical language (Michael Boyle, Victoria Cancer Clinic, personal communication, March, 1995).

After the initial diagnosis and recovery from shock, the diagnosed person faces the next issue which is: 'Now what can I do?' It is at this point that a counselling tool

based on the experiences of a number of individuals who are experienced in the cancer culture would be helpful to both counsellors and clients. The words of those women who have 'been there' written in an ethnographic report would be valuable information to those in counselling. For instance, under the stress of the diagnosis and treatments, clients often indicate they think they are 'going crazy' because they can no longer concentrate, read, watch movies, or tolerate social occasions. Clients, and their families, want to know how other, so-called 'ordinary,' women handle the stressful experience of living with breast cancer. Autobiographical 'success' stories are presently available but often have limited appeal since many of the cancer clients cannot immediately identify with the 'kind of woman who can write a book,' and/or their health precludes reading long texts. Sometimes the message from the autobiographies are at odds with the clients' experiences as in this example. Wadler states:

Mano a mano, eyeball to eyeball. This is a modern story. Me and my cancer. I won.

As for the mark on my left breast, I am happy to have it. It is the battle scar over my heart; and if no one but my doctor and the girls at the gym have seen it lately, I am certain, believing as I do in musical comedies, that somebody will soon.

"So, how'd ya get that?" he'll ask, our first lazy morning, and I'll say, delighted he has found me, "Glad you asked, 'cause it's a wonderful story . . ." (Wadler, 1992, pp. 2, 166).

Clients I spoke with experienced continued fear and terror from the time of their diagnosis to as many as 47 years later, as in the case of one informant, Vera.

Just when clients want to ask questions most, they learn to be silenced. Asking for information often earns a woman the label of 'difficult,' as described by Denise Forest, an informant who wants her own name used:

I didn't get any of that information from the medical profession, not one ounce . . . Not one thing about what I could do for myself. . . . When I saw my GP I said: "Is there anything that people can do in terms of diet and stuff?" and she said: "No."

. . . And secondly why even say to a person, "That won't help." Why disempower somebody like that?

. . . I had already been down to see the cancer clinic and I had asked a lot of questions about chemo . . . And I wasn't 100% sure that I was going to go ahead with it . . . And he (the doctor) did this number where he said: "I know all about you. I've gotten all the records on you."

"I know what you are thinking." He said. He knows what I'm thinking?? He knew what I was thinking?? He couldn't even speak English properly and he's telling me that he knows what I'm thinking?

And so, take somebody like that surgeon. Forget it. I wouldn't tell him anything about myself that I didn't need to tell him. And I didn't at BCCA because I didn't really have the sense that my personal life was of any interest to them.

One response of the medical profession to patient request for help is to refer clients for group therapy. Note that doctors rarely suggest non-medical supports, though this is in the process of change (Olivotto, Gelman & Kuusk, 1995). This addresses the need for information only in a limited way, since the emphasis in group, (often at group members' requests), is usually on learning Relaxation and/or Visualization Skills. The taboo about speaking about one's cancer in this culture is powerful, clients tell me, but talking about stress is completely acceptable.

Enculturation into the world of being a breast cancer patient begins with receiving the medical diagnosis. The impact of the diagnosis is experienced in some or all of the

following aspects of their lives: altered interpersonal relationships; loss of independence and the creation of dependence on medical experts and others; sexual image and body integrity; life disruption, and existential issues. These are named the five “D’s” by Rowland (1989): distance, dependence, disability, disfigurement, and death. After accepting the diagnosis, one of the prime enculturation tasks in becoming an experienced cancer patient is learning how to cope with having cancer. One of the first lessons for each is to practice or learn the cultural rule of silence around cancer. Each finds she has to learn what can be talked about (and with whom) and what cannot. For example, Carol, an informant, tells us:

They did the bone scan, and I said to the technician, “What are the results?” And she went into, “Oh, you know, we’re not allowed to do that, blah blah . . .” And I said, “Look, I’ve been diagnosed with breast cancer. I’m going in tomorrow for surgery. Now you’ve got an option. You either tell me or I’m not moving from this Outpatients.” And I could see this look, “Oh my God, have we got a right one here.”

So she went away and she came back with another technician. And she went into the same spiel. And I said, “I’m not moving until I see a radiologist.” I said, “You have a choice, you either take me to the radiologist or I’m sitting here”. I wasn’t rude. I thought, “Don’t give me this garbage, I don’t have time for it.” She went away and she came back and said, “The radiologist will see you.” So I went in and he said, “Why were you referred in the first place?” So I told him. And he said, “Where are those x-rays?” I said, “I brought them over. I don’t know where they are.” I said, “But something was showing up. I could see something . . .” And he looked at me, and he said, “You could?” And I said, “Yes, I could.” “Just a minute.” he said. So he went away and he came back and he said, “Come with me.”

He took me into the viewing room and they had my bone scan. And, have you seen bone scans? They’re so neat. Because this was just before Halloween, and they’re about this size, and it’s your own tiny little skeleton in miniature. They’re really neat. So I said, “How do you manage to read those? They’re so tiny.” And he explained to me, that if there is anything, either arthritic or some cancerous lesion, it shows up as a sparkle. It sparkles on the screen.

This man was from Ireland, and I'm originally from Scotland. And when I'm really stressed, my accent is quite broad. So he said to me, "Where are you from?" And I said, "The west coast of Scotland." Well, he said, "I'm going to tell you the result." And he's whispering. He said, "Now, don't tell anybody I told you because I'm not supposed to tell you." And I said, "That's all right. They're my bones, I need to know." So we were laughing. And he said, "Everything's clear. There is no problem." I said, "Thank you, thank you." I did not want to think that I'd already had some metastases, you know.

In breast cancer, the veil of silence is only now beginning to be lifted as women are speaking out (Hart, 1993; MacPhee, 1994; Wadler, 1992; Williams, 1993). Women in feminist literature are also beginning to speak out about their experiences with the medical profession (Behar, 1991; Razak, 1993). Many women told me they retreated totally into silence until they came to counselling. They found they were enculturated in that they had to learn 'how to be a patient' and how to be patient with their new role of being an ill person (Batt, 1994; Mathieson, 1991). For many women there was a struggle with how to change from being independent to being dependent on others.

Anne Marie, an informant, states:

Then you go to the Cancer clinic and you've heard this again and again, that they get you ready. Then they wait. And then you go and you get on the table. And this is a little stressful. I think women should be told what they're going to be doing before they get to this stage. Someone should say, "You are going to be lying face down on the table and that table has an actual hole in it, where your breast goes through." It's a bit like you go for an oil and lube, like a car, and they're working underneath you and you feel like a cow, sort of. . .

They're working all this out, and the process of, you're very, your knowing that there's a few people there. But nothing's really said because they're so intent on what they're doing. They don't realize they should be saying, "Now this is what we're doing and this machine is this, and the computer, and what's going on. Do you want to know or don't you want to know?" Because I want to know. I'm in the medical field and I want to know what they're doing down there. Anyway, so that took time. They put that wire in, and then you had to go back to your little area where you are kept waiting for the next process, for the surgery.

That's a problem, because in that situation, you've got to lie there for a long time, because they're holding you in bay until you actually can go for surgery. So you're sitting with this wire out and you're waiting, waiting, waiting . . . And you've got a 2 hour wait before you go to surgery. I think they should let you know that, too.

Now, they tell you to bring things in to read because you might be waiting, but at first they won't let you know that you're going to have the whole day there. They tell you that you're going to go home earlier, but with most gals, they do have to stay and have that wait because there's a problem with the O.R.s and everything, to be able to get it all through. So anyway, you wait, and then you go for your surgery. Then you get the chest wall block. I think that was one of the more traumatic things for me because I didn't know anything about the way these fine wires were done in that way.

So you're lying there with questions. Yet you feel you can't say anything because you've got your head down and aren't able to speak. And this (breast) was hanging through while they're putting the fine wire in . . .

Confusion was often the result of change in normal (before cancer) cultural rules about living. Expectations were suddenly altered for clients about how to please professionals who would 'help or cure' them, and for family members who suddenly found roles reversed--that they were required to care for the primary caretaker.

Coping with Cancer

Our North American society minimizes, denies, and rejects death. Our culture also denies aging and sickness. Since cancer is equated with pain, suffering, and death, denial sometimes is an option clients and/or their families choose. However, treatments (surgery, chemotherapy, radiotherapy, counselling/psychotherapy) are available. Some individuals have been known to survive cancer despite its bad press. Complete denial surrounding a cancer diagnosis is unlikely, though it does happen occasionally. The taboo and stigma around cancer exist on many levels. Even hospital staff talk and write about

cancer in euphemisms or scientific/medical language such as: 'ca,' 'neoplasms,' 'stages,' etc.

When in France in the summers of 1995 and 1997 at Health Psychology conferences, I noted that North American physicians who work with cancer are called Oncologists, while in France, the humbler and more direct labels of 'Cancerology' and 'cancerologist' hold sway. Our North American media/info world shows us young, healthy, whole, people. Where are the aging, the disabled, the sick? Rarely, they are seen, of course, advertising a specific item for their target group.

In cancer counselling, I have found that both counsellors and clients indicate that they want to know how other people live with a diagnosis of cancer. Yet much of the literature (both research and popular) continues to be written from the etic or outsider's point of view. Most often research or popular writings do not originate from the individual's experience, or emic point of view; in the small body of literature which does exist, personal cancer client writings tend to be about the experience of remission (Carter, 1989; Wadler, 1992). Yet remission is not the reality for many with cancer. Instead, in the enculturation process which takes place after one receives a diagnosis of cancer, imagination and the unknown march together down the path of everyday living. As the French poet and diarist Anais Nin states:

To imagine was far more terrible than reality, because it took place in a void, it was untestable. There were no hands with which to strike or defend oneself in that inner chamber of ghostly tortures. But in living the realization summoned energies, forces, courage, arms and legs to fight with so that war almost became a joy. To fight a real sorrow, a real loss, a real insult, a real disillusion, a real

treachery was infinitely less difficult than to spend a night without sleep struggling with ghosts.

The imagination is far better at inventing tortures than life because the imagination is a demon within us and it knows where to strike, where it hurts. It knows the vulnerable spot, and life does not, our friends and lovers do not, because seldom do they have the imagination equal to the task (1973, p. 101).

Without knowledge, and in silence, imagination can terrorize. Cancer is equated with death and silence, pain and suffering, and since these are minimized in our culture, the word cancer often produces terror in the imaginations of cancer clients and their families. Cancer represents the unknowable, the unspeakable, the insupportable. Many cancer clients are desperate to talk about their anxieties and anguish since they believe sharing helps their health (Pennebaker, 1990). At the same time, paradoxically, many experienced being silenced. They want to talk. No one wants to hear.

In my experience of working with women with breast cancer, I found the extreme stigma of this diagnosis and the taboo about talking about having breast cancer are major stressors which create barriers to coping. Every person with a diagnosis of cancer emotionally experiences the threat to life and well-being uniquely, and each person with such a diagnosis must cope or learn to cope with this new situation. Elaine Zyri, an informant who also wants her real name used, suggests that stress in her life was a causal factor in her diagnosis of breast cancer:

. . . it was a pretty horrendous upbringing. Anyhow, to get back to it, I would say that my breast cancer is due to the stress of my life in not knowing how to cope with it. And I think my ongoing recurrences are that, also, because it's been very stressful living in the house where I'm living. I don't get very much support and I try the best I can not to get involved with what's going on there. But it does, in some way, affect me.

And I would have moved out this summer after D. got a little heavy-handed with me, but I ended up having another recurrence. And I couldn't see moving out on top of all of that. But I am planning on leaving this situation some time once my health gets sorted around. I think I would say that my breast cancer is basically due to a suppressed immune system and not learning how to cope with stress properly.

Lipowski (1970) defines coping as all cognitive and motor activities which a sick person employs to preserve bodily and psychic integrity, to recover reversible impaired function, and compensate to the limit for any irreversible impairment. White (1974) defines coping as adaptation under very difficult conditions, whereas Lazarus and Folkman (1984) define coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. Women with a diagnosis of breast cancer want to improve their ability to cope with this new threat to their integrity. One of the first tools they need is more information on how others 'in their shoes' have coped. *This study addresses that need by sharing the universal themes common in the language used by cancer clients describing their experiences and illustrating how they have coped.*

A description of several theoretical models of coping behaviours follows. The standard biomedical model in North America is the one in which medical experts take over and patients are directed to and expected to comply with the medical instructions (Mathieson, 1991). Another is the 'adaptation model' (White, 1974) which has three characteristics. The first characteristic, defence, is concerned with danger and safety; the second characteristic, mastery, has to do with personal sense of success and performance in meeting task requirements; and the third characteristic, coping, deals with difficult or

unusual situations for which new strategic maneuvers and instrumental behaviours are required. Coping works towards resolution of the problem, while defence attempts to avoid or deny the issue. Mastery is often relegated to creative adaptation. It is precisely because women find it difficult to experience any degree of mastery in the course of their treatment(s) that coping becomes difficult. The role of the patient is largely a passive one if she is appropriately compliant, despite some research which suggests that 'fighting spirit' was an advantage in coping.

For example, although there are studies on coping with cancer (cf. Derogatis, Abeloff, & Melisaratos, 1983; Greer, Morris, & Pettingale, 1979) which showed that 'fighting spirit' had a positive impact on coping, other researchers, using more sophisticated research models and controlling for confounding variables, have found no impact on coping and outcome of disease (Cassileth, Lusk, Walsh, Altman, & Pisano, 1987; Holland, Korzun, Tross, Cella, Norton, & Wood, 1986; Jamison, Burish, & Wallston, 1987). To date, no research has demonstrated clearly that there is a correlation between fighting spirit and health.

Cancerphobia

As a cultural phenomenon, fear of cancer appears to be universal (Patterson, 1987). For some, denial of the cancer diagnosis is a coping strategy used by an individual and her family and friends (Matt, Sementilli, & Burish, 1988; Wool & Goldberg, 1986). In today's global village, it is not surprising to find that social taboos and prejudice of this disease are widespread. This cross-sectional ethnography represents the cultural scenario for women in North America, a scenario described by Patterson:

As ever cancer loomed as an alien, surreptitious, and voracious invader that seemed to attack anybody, anywhere, and to advance relentlessly until it killed its victims and impoverished their families. This dreadful vision of the disease, like so much else in the modern cultural history of the malady, continued to be confirmed by the personal experiences of millions of families. Medical advances notwithstanding, popular fear has remained one of many enduring realities that have highlighted the story of cancer in American culture since the 1880s. Despite the rapid pace of change in the past century, this fundamental concern has indeed stayed much the same (1987, p. 310).

It is important to note that cancerphobia, or fear of cancer, is common across many cultures. For example, Augustine Quashigah (1997), from Ghana, discussed the cultural stigma about cancer in Africa. She stated that: *“In Africa, cancer is known as an ailment without cure and people fear to associate themselves with cancer or any related sickness.”*

She speaks of her responsibilities in nursing someone with cancer and how relations and friends tried to avoid both her and her client.

Another example of extreme cancerphobia is described by Dr. Rasiz Sultana (1997) from Dhaka, Bangladesh, at the World Conference on Breast Cancer:

A large number of women in Bangladesh are either suffering from or dying of breast cancer. Women, mostly of rural origin, or illiterate, are shy to show their bodies to the physician, male or female. They think it unethical. Most women, rural or urban, are also ignorant of this disease and its symptoms. Even, they dare not utter the word *breast* or *breast cancer* in Bengali in public. They don't even know of physical examination or other advanced technology of early diagnosis. Cost of clinical examinations are also too high for them. Even if it is detected, it is not properly treated or timely operated upon. It is also unfortunate that the husband and other relatives also do not treat her sympathetically.

Major reasons for this sad story in that society are social taboos and prejudice, illiteracy, ignorance of the disease and its treatments, or of final consequence.

Enshrouding most interactions of cancer patients is the cultural attitude towards talking personally about cancer. This is a major issue in cancer counselling, occurring when a client asks for help to break the cultural taboo of speaking about her diagnosis of breast cancer. Though attitudes and behaviours about breast cancer are culturally defined, it is important to note that fear of cancer is ages old. Over the centuries, dread of cancer has stigmatized those with cancer (Holland, 1989). In recent times, media coverage has raised this fear to new levels, particularly with the sensational coverage of disastrous environmental events such as the Love Canal and Chernobyl. Here is an comment on the media-induced fear of cancer:

American cancerophobia, in brief, is a disease as serious to society as cancer is to the individual--and morally more devastating. For this state of affairs, many are to blame--not only high pressure advertisers foment and exploit our cancerophobia, but also the well-meaning but yet baneful practices of other groups: activist consumer organizations, politicians, and even the American Cancer Society, which points dire accusatory fingers at you if you do not give money to "cure cancer."

Among the guilty are the media. Because of our society's disease, any news about cancer, no matter how trivial, is ipso facto sensational. Whether it is the latest tentative suggestions that some agent or condition is oncogenic, or the most recent molecular definition of the cancer cell's wall, the media treat the tentative indictment as if it were an actual catastrophe, and the minor laboratory discovery is heralded as another "breakthrough" in our "war" against cancer.

So the vicious circle spirals upward and outward: cancerphobia elicits sensationalist reporting, which in turn fosters the demonology of cancer (Inglefinger, 1975).

Women who are diagnosed with breast cancer find themselves set apart from the norm initially by virtue of the language which is used when discussing cancer. Their path outwardly has diverged from that of an individual in the mainstream culture, walking, talking, and living in the land of the normal folk, to the trail of the subculture of those with cancer, having to learn to walk and not talk in the land of those with cancer.

Cultural Messages about Women

A diagnosis of cancer changes both inner and outer landscapes for each individual. The 'inner journey and landscape' of breast cancer is often highlighted with fear and courage. From the individual's perception of the illness, it appears as an attack on the integrity of the body as well as on the core of self. Denise Forest is quite clear about the discrepancy between the way her body feels and the information that she has breast cancer:

In a way, I'd just as soon not know that this disease is still inside of me somewhere. Because I don't feel it there. My body doesn't say it's there right now. And it's crazy-making because my body says I'm healthy. And why should . . . You see, a hundred years ago this would never have happened. Why should some information that some person has handed me on a piece of paper change that? I should be able to live with what I feel right now.

North American media sets out and maintains cultural models illustrating the ideal and selling it as the norm. Jean Kilbourne (1979; 1987), in her presentations on images of women in media, describes how we are regularly bombarded with images that define our cultural values and concepts. Advertising tells us who we are, or at least, who the media and the ads think we should be. This, for many, leads to feelings of guilt and inadequacy if we are different from the presented image/product. Advertising shapes our attitudes and

thus affects our behaviour. Women are particularly molded by cultural messages in advertising because women's magazines are virtually all advertising. Gloria Steinem, in 1990, (cited in French, 1992) counted the pages of actual content in a variety of American women's magazines, including letters to the editor and horoscopes, versus pages of ads and 'complimentary copy' which are articles written to advertisers' specifications. For 1990, she found the April edition of *Glamour* contained 65 pages of real copy out of 339 pages; the May *Vogue* contained 38 pages of real copy out of 319; and the March *Family Circle* had 33 pages of real copy out of 180.

The assumptions about women mirrored in advertising tends to separate women into two basic categories: housewife and sex object. If the woman is married, she is the hypothetical heroine of many marketing strategies for the stereotypical housewife aged 18 to 49. No one knows what happens to women over 50 since they are rarely portrayed. Women in the ads demonstrate a psychopathology of cleanliness--that their greatest joy in life is having the whitest wash, the cleanest dishes, and the glossiest floors. In fact, the ads sell cleansers so efficient that their use renders the floor 'clean enough to eat from' (Bartos, 1982). Each woman's greatest hope (it is assumed) is to make a cup of tea or coffee her husband and/or mother-in-law will find acceptable. If she is single, it is presumed that her major preoccupation and life goal is to get married. So she is sold perfume, makeup, and sex-enhancing clothing to catch her man. In many ads for women, the underlying message is buy, buy, buy something that will ultimately have the effect of pleasing her man. Images and words accompanying the ad (copy), often suggest that the product will make the purchaser (female) more attractive to men. The assumptions are

that women need a male somewhere in their world to be considered complete. Although advertising has belatedly become aware that many women work outside the home, there is an unspoken assumption that partners and families still have priority with women, emotionally, and physically.

Kilbourne (1987) states that women learn to objectify themselves and learn that beauty defines their worth. Beauty is cultural, it is something learned and acquired, not natural. Faces are turned into masks and bodies into objects. Ideal female beauty is portrayed as flawless (usually airbrushed) perfection; for example, youthful faces have no expression, no wrinkles, and no pores. Most ads portray an inhuman standard that may be aspired to, but cannot ever be achieved. The female body and sexual connotations are paired in the marketing of many products and services.

Key (1976) states that sex is embedded (a technique used to disguise information) in many ads. Subliminal stimuli (consciously unperceived words and picture symbols purposely designed into ads with the motive of soliciting, manipulating, modifying or managing human behaviour), he suggests, account for many of the values of our culture. He postulates that the subconscious of the perceiver has taken in the messages of the ads and unwittingly provides perspectives or a *cultural bias* through which we evaluate data on a conscious level. Key claims that the average North American woman, who is exposed to many hours of media per week, learns that she is basically *inadequate*. All other women appear more sophisticated, more healthy, more beautiful than themselves, by comparison with the images in the media. 'Everywoman' learns to work at attempting

to achieve the portrayed ideals through buying more, ever more, products and services devoted to her 'improvement.'

Cultural Messages About Breasts

North American media sets and maintains the standards for many cultural values (Kilbourne, 1987). A woman's self-image is often measured against the cultural norms established by the media. That individuals have little power to change or modify their biologically-programmed physical dimensions is generally ignored. In fact, Kilbourne (1987) states that the reverse is true, with some ads exhorting women to work harder at changing themselves, subtly suggesting that somehow they just aren't trying hard enough. Young women with small breasts, for example, are quite likely to perceive themselves as deficient in personal value when confronted with a lifetime of ads showing females with large bosoms. As Sheila, an informant, states:

Well, as I said, if you've never been beautiful, somehow it doesn't bother me at all. I think if I'd been a beautiful woman with a marvelous figure and breasts, it may be could be a bit more disturbing. But I did not have a fantastic figure. Though, mind you, around 1989, I started to get a bosom, I hadn't had much of one until then. I think it's because you're getting towards menopause. I went through menopause in 1990, and I must admit, I was just a little bit proud of these breasts that I had acquired, and I used to think, "Wow, isn't that marvelous." So I think God got even with me and thought, "This woman is too proud of these breasts. She's going to have to lose (one)."

Feelings of guilt about body inadequacy produce consumers who want to fix whatever 'is wrong.' And as one client said, 'whatever I have, it's never right.' So, of course, there are endless 'new' and 'newer' products to help with the 'deficiencies'. That the products can never produce biological change guarantees failure. So the ads urge yet more schemes to

attempt to bring the fantasy portrayed into reality. Thus the cycle of inadequacy, failure, guilt, and buying hope continues. As a result, many women experience depression, self-rejection, frustration, and almost inevitably, *go back to buying more new things*. Women and shopping is a standard theme in our culture's humour. One of the most frequently heard comments from women who have had surgery to enlarge their breasts is: "*I want to feel good about myself*" (A. J., Client, personal communication, October, 1995).

North Americans are often astonished to discover that the breast is not a primary erogenous stimulus in many of the world's cultures, including several where female breasts remain uncovered in public. In North America, the idealized shape and contour of large youthful breasts assail us from newspapers, billboards, magazines, movies, and television. The media has convinced the public that the symbol of the breast is sexual. That breasts are only one physical aspect of women of all ages, sizes, and shapes is basically ignored.

Biologically, there is no such thing as one norm for natural breast contours. In North American media, however, there is only one right breast size. The standard breast shown by the media is a 38D and exists in reality in only 1.6% of North American women (Key, 1976). The ubiquitous portrayal of these abnormally large breasts superimposes an unconscious ideal in most women's minds which can only be achieved in fantasy. Our cultural reality is that breasts are symbols of femininity and sensuality and are represented by such media icons as Marilyn Monroe, Dolly Parton, Jayne Mansfield, and the Playboy Playmates. The effect of these cultural messages about breasts for many women appears to be that large (emphasized) breasts are essential for a positive body

image. For women with breast cancer, women who may never have queried the assumptions they held about their healthy (not the media stereotypical) breasts, the diagnosis of breast cancer is genuinely stunning, often horrifying. When the cultural stigma of having a deadly disease such as cancer is connected to a woman's breast, her visible symbol of femininity, individuals often experience an identity crisis. Yolande, an informant, told me that it wasn't the loss of her breast that was so difficult--it was the loss of who she really was:

Oh, yes. You know I've never articulated it. What I have brought to consciousness is not so much loss of beauty or anything like that, but loss of who I really am . . . I think that being married to my husband made me depressed. Then after losing my breast, that just really doubled it up. But I think that something happened to me. I have said that to myself, something happened to me, and that's why . . . this trip to the doctor today. About two weeks ago, I thought: "God damn it, I'm sick to death of this. I'm going to get on with trying to find, trying to get to the bottom of this crap." You know, when I get mad I get foul-mouthed.

All clients know much tacit knowledge about having cancer. Each had to learn it alone. Every person diagnosed with breast cancer has to invent his or her own wheel of facilitation into the culture of having cancer. Since men do have breast tissue, they can also develop breast cancer though their numbers are few (Olivotto, Gelmon, & Kuusk, 1995). Every individual finds a way to narrate his or her story within the parameters of one's culture. Gergen and Gergen (1988) suggest that one is not at liberty to select any identity; that cultures encourage some and discourage others:

Danger results from confronting the potential for sudden loss, destruction, death, and the like. All such events propel one suddenly toward or away from a valued goal or end point in the narrative sequence. Suspense and danger are thus the result of anticipated narratives (p. 27).

From my personal experience, cancer clients are greatly constrained in telling their story, even in group therapy. They are in suspense and danger. They do not know whether they will survive or not. They attend group counselling for many reasons; one of the most frequently stated was ‘to meet others who are in the same situation.’ Yet so strong was the prohibition against talking about ‘it’ (cancer), that the focus of a group often turned, at the group’s request, to ‘coping skills,’ or other cognitive or behavioural strategies for dealing with ‘stress’ (not with cancer, just stress!).

The Biomedical Model

Some women with breast cancer at the hospital clinic stated that they felt dehumanized in the medical settings, such as in Sharon’s experience of being treated as ‘a piece of meat.’ Others experienced being ‘reduced’ to a decontextualized diagnosis and treatment protocol, such as in Margaret’s being called ‘a 45-year-old mastectomy.’ Some physicians are beginning to move from the predominantly biomedical model towards a more multidimensional approach (Engel, 1977; Kimball, 1981; Reiser & Rosen, 1984). Contrasting the bio-psychosocial perspective with the biomedical, Silverman and colleagues state:

Derived from molecular biology, the biomedical model assumes that all disease can ultimately be explained in terms of deviations from norms of measurable biological processes. Such a model at once removes disease from its psychological and social contexts and explains all physical and behavioral abnormality as the result of disordered biochemical or neurophysiological events. In so doing, the biomedical, in distinctness to the bio-psychosocial, model fails to consider the “crucial stabilizing and destabilizing potential” of intrapsychic, interpersonal, familial, cultural, and societal phenomena in the development, expression, natural history, and outcome of the patient’s disease . . .

In addition to placing limitations on the physician's understanding of the cause, course, and treatment of the disease, the biomedical model may also serve to depersonalize the practice of medicine and encourage the doctor to neglect the patient's subjective experience of his or her illness as a critical source of data. This in turn may lead the physician to place undue emphasis on more impersonal technical diagnostic procedures and on laboratory measurements (Silverman, Gartrell, Aronson, Steer, & Edril, 1983, p. 1154).

A small percentage of women in counselling have perceived the biomedical perspective as a form of abuse. Denise Forest says:

I have had a localized recurrence in the last few weeks. This was a risk I took when I refused the radiation therapy. I have done breast self-examination religiously since my first occurrence so caught this one very quickly. (It was quite close to the last one.) I saw the same obnoxious surgeon. He actually shook his finger in my face and said: "You are playing with fire!" He informed me that my health regime was doing no good. (He could say that of the chemo as well!) I was planning a trip to Europe and did not want to give it up, as with this disease, I do not know if I will have another chance. The surgeon suggested that I may be putting myself at risk by putting off the surgery until my return. However, when we set the surgery, it turned out that he would be on holiday and would be unable to do the surgery for 2 or 3 weeks after my return. (No talk of increasing the risks in that case.) Again, I left very disempowered and devastated.

I had formed a relationship with an allopathic doctor who has left conventional medicine to study alternatives and he was able to arrange immediate surgery (using a local anesthetic, which had been my request--refused by the arrogant surgeon) with a friend of his in another town. I had the surgery, drove home that day, felt fine in 24 hours, and went on my trip to Europe. I will not see the surgeon here again. Whatever his skill is, it is not worth it to be treated with disrespect and cruelty.

Others have experienced varieties of abuse prior to their diagnosis of breast cancer as children, adolescents, or adults. Some state they feel victimized and silenced by the authoritarian system in the medical hierarchy in ways which parallel the ways in which they were previously silenced by more powerful offenders (Lorde, 1990). Brookes

(1992), a feminist, discusses how abusive experiences silence women. Medical facts do not always have meaning, especially for one who does not have enough self-confidence to ask for clarification if and when it is needed.

In the same vein as the biomedical model, the current recovery (post-surgery) model may also be perceived as abusive. Some individuals with breast cancer are beginning to reject the patronizing post-mastectomy recovery model which sends a volunteer to the patient after surgery to offer a wad of cotton padding and the words: *"Just put this in (your bra) and no one will ever know."* This form of denial is mind-boggling to some post-surgical patients who have just lost one or two breasts to breast cancer surgery. One woman in that situation said:

"How ridiculous! I know the difference! And so will my partner and my family and my friends..."

Lorde (1990), a black writer and poet, also denounces breast prostheses:

Prosthesis offers the empty comfort of "Nobody will know the difference." But it is that very difference which I wish to affirm, because I have lived it, and survived it, and wish to share that strength with other women. If we are to translate the silence surrounding breast cancer into language and action against this scourge, then the first step is that women with mastectomies must become visible to each other. For silence and invisibility go hand in hand with powerlessness (p. 61).

And though women with all different colours of skin undergo surgery for breast cancer, only pink prostheses are available. Who is going to challenge the insularity of this approach, since the women themselves tend to go inward, isolate themselves and save their energy for healing? Women with breast cancer state that they feel separate from the mainstream culture. They talk of the stigma of having a diagnosis of cancer and specifically, the taboo of having breast cancer. Almost everyone 'knows of someone with

breast cancer who died'. Clients state few listeners wish to hear about the experiences of someone currently living with the disease. Carol, an informant describes what happened for her:

And that was the thing I noticed around that period that it did hurt, that female acquaintances did not come out. They sent cards, they sent flowers, they phoned, but they couldn't come to visit me, for whatever reason.

It's a sense of, I think it's a sense of shame. There's a sense of, and this, I'll just say it, there is a sense, too, maybe this really is what I am. You know, maybe this really is what I am, and all these years I've been living a false thing. But in fact I really do feel I am stigmatized and I should be because I'm not really worthwhile. There is very much that, it's there, it really is there.

It's just, there's a sense because of that, you've got to try to convince people that you are still all right as a person, that you're a fully operating person.

Other women with breast cancer told me they wanted to break out of the silence surrounding having breast cancer. As one client stated: “*I want to come out of the breast cancer closet.*” In an essay entitled “The Transformation of Silence into Language and Action” in The Cancer Journals (1990), the late Audre Lorde talked about her greatest regrets--her silences. She felt silenced by the stigma and process of breast cancer. She beseeches women with breast cancer to examine and confront their fears of becoming visible, of speaking out. This study is one way of encouraging women with breast cancer to share their experiences to break out of the prevailing silence.

Ethnographic Methods

Ethnography is an exciting enterprise, the one systematic approach in the social sciences that leads us into those separate realities that others have learned and use to make sense out of their worlds. In our complex society the need for understanding how other people see their experience has never been greater . . .it

offers health professions the opportunity of seeing health and disease through the eyes of patients from a myriad of different backgrounds . . .

Ethnography offers all of us the chance to step outside our narrow cultural backgrounds, to set aside our socially inherited ethnocentrism, if only for a brief period, and to apprehend the world from the viewpoint of other human beings who live by different meaning systems. Ethnography . . . is more than a tool for anthropologists to study exotic cultures. It is a pathway into understanding the cultural differences that make us what we are as human beings (Spradley, 1979, p. iv).

At times it seemed as if I were involved in an actual ‘culture of cancer.’ This notion of culture was so strong that I began to investigate how our predominantly white western culture deals with someone who has cancer, and breast cancer in particular. The woman with a diagnosis of breast cancer has many issues in her life to contend with such as anxiety, fatigue, and possible debilitation. Thus, I wanted to pursue research about living with breast cancer in the most respectful way possible. What research methodology would be the most respectful, yet the least intrusive, for a person with breast cancer? After some thought, I reformulated this question and asked: What research method offers rigorous scrutiny of clients’ truths, scientifically, within the cultural context of having a diagnosis of breast cancer? Ethnography’s task is to describe a culture.

Culture . . . refers to the acquired knowledge that people use to interpret, experience and generate social behaviour (Spradley, 1979, p. 5).

Ethnography explores the cultural context and meaning-within-context as well as illuminating the roots of power from which meaning and context grow. Culture is shared knowledge, some of which is tacit, beneath the surface of words, yet clearly understood by those who share the culture. An example is when breast cancer clients learn silence.

Other cultural knowledge is explicitly shared through instruction, verbal and written. All ethnographies are partial, as are all research studies. Ethnography is a method of research process which opens to the public eye that which it explores. The result, the written ethnographic report, is validated by the audience of readers, the informants themselves, the public, and the research world. As the ethnographer, I had to “*rely on the supposition that people in a shared cultural and linguistic community, name and identify their experience in a consistent and shared manner*” (Von Eckartsberg, 1986).

The ethnographic method of questioning results in the legitimization of both tacit and ordinary knowledge. It is the decoding of one culture in the process of recoding it for another (Van Manen, 1988). The ethnographer’s task is to record meaningful social language:

If one recognizes that meaningful social life is produced and reproduced through the use of language, then one must also recognize that language is constitutive of how social life is represented. This has particular force for the ethnographer. There is a direct parallel between the methods of everyday understanding and the methods of ethnographic inquiry.

We look, listen, and ask; we develop ideas and try them out; sometimes we join in, and sometimes we hang back and observe... The ethnographer uses the methods of everyday accounting--narratives, descriptions, metaphors, analogies, and examples--to reconstruct the social worlds . . . (Atkinson, p. 12, 1992).

Ethnography has been used as a methodology in a variety of health issues and though full ethnographic studies may not always have been possible, a specific set of data about one part of a culture may illuminate the larger cultural scene (Boyle, 1994; Morse, 1989; Thorne, 1991). This research objective is to have the experiences of 13 women

teach us about the subculture of being a breast cancer patient within the larger western industrialized culture. In utilizing ethnographic questioning, I was particularly interested in this possibility of interpreting the emergent data in the context of the larger culture. I did not enter a larger cultural field site, but entered the field of each informant, each in a setting of her own choice. I adopted her point of view. It is this highly personalized research format which suited my need to have the research as minimally intrusive as possible, given the sensitivity required to work with individuals who are vulnerable.

By using this method, I was able to give each informant full control of the interview. Guba and Lincoln (1989) contributed support for my concept of research as a route to an action. The themes which emerged in this ethnography form the basis for a counselling tool for future breast cancer clients; it is my objective that this information may help normalize the awfulness of the diagnosis in that unspoken issues may be brought forth and discussed, not left to simmer inside the client. Moreover, the clarification of the research act--that it is the orchestration of a negotiating process, rather than the gathering of facts by a technician--intrigued me. With the concept of the clients' welfare and dignity foremost, I wanted the research to take place with the utmost respect for each individual's integrity and privacy. Furthermore, Guba and Lincoln (1989) commend full participant involvement: participants have full parity and control with the researcher in the research process. The idea that constructions are linked to environment, and that outcomes are not description of the 'way things really are or really work,' but are representations or meaningful constructions that individuals form or create to make sense matched my thoughts (Guba & Lincoln, p. 8, 1989). When I combined this with the

understanding that constructions are shaped by each individual's values and realities, I realized I had found a method, ethnography, which fulfilled my research requirements.

Ethnography is a vehicle used to translate meanings embedded in the language of one into the language of the intended audience (Denzin, 1989). A research report using the ethnographic method of questioning demonstrates how the experiences of those with breast cancer is both shaped and thrown into figure/ground relief by the dominant culture (Spradley, 1979).

Breast cancer clients each negotiate their lives within the cultural context which is embedded within the larger culture. Goetz and LeCompte (1984) define the process of ethnography this way:

Ethnography is . . . a way of studying human life. Ethnographic design mandates investigatory strategies conducive to cultural data; they represent the world view of the participants being investigated, and participant constructs are used to structure the research. Second, ethnographic research strategies are empirical and naturalistic. Participant and non-participant observation are used to acquire firsthand, sensory accounts of phenomena as they occur in real world settings, and investigators take care to avoid purposive manipulation of variables in the study. Third, ethnographic research is holistic. Ethnographers seek to construct descriptions of total phenomena within their various contexts and to generate from these descriptions the complex inter-relationships of causes and consequences that affect human behavior toward and belief about the phenomena. Finally, ethnography is multi-modal or eclectic; ethnographic researchers use a variety of research techniques to amass their data (pp. 3-4).

In order to explore cultural norms around illness and cancer, I set the stage by asking women to describe their experiences. To begin with, many women had experienced no symptoms of illness whatsoever before the finding of 'the problem' (the breast lump or breast thickening, or breast skin wrinkling--peau d'orange). Each stated that once she was diagnosed, everything seemed to change. Each experienced her place in

the culture of healthy folk disappear, to be replaced by membership in a completely uncharted land of fear and ambiguity. The ethnographic methodology enables me to view, through the informants' words, phrases, and language, the intimacies of their life experiences with breast cancer.

By restricting the definition of culture to shared knowledge, we do not eliminate an interest in behavior, customs, objects, or emotions. We have merely shifted the emphasis from this phenomena to their meaning . . . The ethnographer observes and records emotional states, but goes beyond them to discover the meaning of fear, anxiety, anger, and other feeling (Spradley, 1979, p. 6).

Patterns of thought and behaviour common to the group elucidate meanings inherent in the experience of breast cancer.

The ethnographic interview is a way of studying meaning seriously--primary focus is on understanding cultural meaning systems--specific methodology designed for the investigation of meaning (Spradley, 1979, p. 7).

Identifying, analyzing, and interpreting patterns is an essential task in ethnography. This research illustrates ways in which the dominant culture superimposes rules (such as denial and silence) on women with breast cancer, as well as showing how different and difficult it is to be a member of the subculture of those with breast cancer. In asking the women to be my teacher, I am paying focussed attention to what emerges in the dialogal conversation between ethnographer and informant. By using the method of ethnography, I listen, record, and interpret the human stories, and so illuminate the similarities which emerge in a diverse sample. And also, the differences:

By going to the narrative ground and celebrating the complications and contradictions, ethnography features variation rather than uniformity or consistency (Agar, 1996, p.70).

Description and interpretation of emergent themes are the objective of ethnography, not prediction. Though generalizability is not formally a goal in ethnographic research, readers, some of whom are the informants themselves, judge the face validity of what they read in the ethnographic report. Has the ethnographer caught the essence of what is happening? Is this ethnographic data useful as information for others who want to know about the experience under study? The ethnographic report, finally, is judged as a product. This product may be useful as general knowledge or for specific situations, such as information for counsellors or counsellors-in-training.

The Rationale for the Study

Breast cancer has a dramatic impact on those who experience it:

Many features of breast cancer contribute to its powerful emotional impact: it is a leading cause of death in Western women; it attacks an organ with unusual personal, interpersonal and symbolic meaning; its course is often uncertain and prolonged; and its treatments, which have become increasingly controversial, threaten a woman's appearance, sexual life, and ability to work . . . The first discovery of a lump or other symptom usually stimulates fears which lead to prompt diagnosis.

Unfortunately, anxiety can also cause patient to avoid medical attention and delay the necessary biopsy procedure. Usually, surgeons respond to anxious patients by proceeding readily to a biopsy. At times, however, anxious patients appear somewhat hypochondriacal, and are given reassurance without a biopsy. Guilt, anxiety or mistrust resulting from a delay in diagnosis and treatment, occasioned either by the doctor or the patient, can colour the patient's entire subsequent course (Peteet, 1984, p. 164).

The significance of this study is multifaceted. First, it has a specific focus: learning from the experiences of women who have been diagnosed with breast cancer. Secondly, it has the potential to contribute meaningful, validating, factual, emotional, and psychological information to those with breast cancer. Thirdly, it will contribute to feminist and women's health literature from the voices and points of view of women with breast cancer. Fourth, it has implications for counselling decisions and interventions when working with women with breast cancer. Fifth, it addresses the paucity of studies examining emergent themes from the language of women with breast cancer. Finally, it is a contribution to knowledge for counsellors and all those working and living with women who have a diagnosis of breast cancer.

The intention of this study is to develop knowledge about the culture of having breast cancer through the narratives of 13 women who have lived with breast cancer. By using the linguistic descriptions of the women as they tell about the structure of their life-events, I maintain a connection with the authenticity of the women's experiences. Through a dialogic process between informant and ethnographer, I discover multiple threads of meaning in the women's experiences. The external and the internal life-worlds of each of the women are represented in the cultures in which they live and are shared with me in their language. Spradley (1979) states that we all live in co-created cultures of reality. My data are from several one-and two-hour interviews with each of 13 informants for a total of 31 taped interview hours. Interviews were conducted between October, 1993 and March, 1996. The method combines the ethnographic questioning process with the

women's descriptions. My analysis and ethnographic interpretation represents the final ethnographic product, the ethnographic report.

To some extent there exists some 'retrospective bias' in the study (Denzin, 1987). Some of the women are speaking of present experiences, while others rely on memory or experience flashbacks. Denzin states:

. . . the experience that is reported upon, even though it has occurred in the immediate or distant past, becomes, in the moment of telling, an account of the self in the present. (Denzin, 1987, p. 31).

This research is a major step forward in the direction of paying attention to what is perceived by and experienced by those living in the world of breast cancer. My task is to separate the common colours and fabrics in each woman's narrative and then create a quilt of cultural patterns for the onlooker. The common areas resolved themselves into a number of recurring themes, and these are presented in Chapter 5. The voices of these 13 women who have had a diagnosis of breast cancer are our teachers. Spradley (1979) states:

"Ethnography is the work of describing a culture . . . Rather than *studying people*, ethnography means *learning from people*." (p. 3.)

Each of the 13 women told me they found the experience of being diagnosed with breast cancer shocking and stressful. Finding that family and friends often responded to the news of the diagnosis with a range of high stress behaviours from denial to terror created a double dilemma for the women. They had to live with their own feelings and experiences as well as 'manage' or 'deal with' a variety of perceived negative reactions at a time when each felt least fit to care take others. One individual stated that she was no

longer seen as a woman; she felt she became 'a woman-with-cancer.' Another, Margaret, discovered at the hospital where she was treated that she was labelled 'a 45-year-old Mastectomy'. She states:

I had heard the announcements over the P.A. system of surgery scheduled for Tuesday a.m.--gall bladder in the blue room and mastectomy in the green room. This was a terrible moment for me. I asked him which surgery I was scheduled for. He told me--mastectomy. I was expecting a biopsy. Dr. L. had not told me about a possible mastectomy.

I was not prepared. Even though I was in shock with this latest news, somehow my brain functioned. I told the intern "I will not give my permission to have a mastectomy performed, only a biopsy." He looked at me blankly, shrugging his shoulders and as he rose from the bed said: "It does not really matter one way or the other." He left the room.

If I was apprehensive when I arrived at the hospital, now I was experiencing total fear. That night I did not sleep. I also had not seen Dr. L. since my admission to the hospital. Tuesday morning I was prepped and delivered to the OR. A biopsy was performed.

Later on that afternoon, while passing in and out of a drugged sleep, I heard Dr. L's voice. He gently told me there was a malignancy found and he scheduled surgery--a mastectomy--for Thursday a.m. Believe it or not, at that moment I was not shocked--frightened, yes. I looked at him for some time and then said: "A patient usually requires preparation before surgery, regardless of how minor. Even if a finger is to be removed. Now I, as a woman, should have been prepared that I was going to lose a breast. You did not prepare me. What are my chances for successful surgery while I was in this state of shock?" He looked at me sympathetically and said "I'm really sorry."

Thursday a.m. I not only had a mastectomy--but the lymph nodes in the axilla were removed. Post-operative care was mediocre. I washed myself with no assistance from the nurse. You must realize that I am right handed and could not raise my right arm higher than my waist because of the surgery. I was on my own.

The third day of my hospitalization, the surgeon-in-chief arrived at the hospital with an entourage of interns. He arrived at my bed and looked at my chart. I was identified not by name but as a 45-year-old mastectomy patient. He had an attitude that is hard to describe. The closest that I can come to is 'cold and not

caring, ' especially for a doctor (remember, I was young then). He asked the intern "Why did she not have a radical?" The intern replied that Dr. L. had had very good results using a modified. The surgeon-in-chief went to the next patient.

The cultural norm of retreating from cancer, of perceiving cancer as a stigma and ultimately, as death, is carried through the actions, words and behaviours of many in our culture. We accept our culture much as a fish accepts the water in which it swims. Each of the women interviewed found herself metaphorically on the shore asking: "Why do I feel so alone?" and "Why do others treat me the way they do?" Thirteen women narrate their partial biographies as each describes her experiences of living with breast cancer.

There was great consistency amongst the women on certain issues. The first universal theme was the experience of shock on finding that one has a diagnosis of cancer. Another similarity across the individual women's experiences was an element of what they referred to severally as the 'shame,' 'stigma,' 'secret,' of having cancer in the specific site of one's breast. The sense of being 'betrayed' by one's body, by the media, by one's lifestyle, emerged over and over again. Above all, there was a common thirst for knowledge about what was happening. Most women turned to the medical specialists and experts who were attending them and discovered overt and covert hostility to questions and information seekers. They learned they needed to seek out knowledge themselves. Because the need for information was great, many women turned to libraries and bookstores. Margaret, an informant, stated:

I read whatever crossed my hands regarding cancer. I wanted to help myself and above all, I wanted to survive . . . After reading an article on the benefits of Vitamin C, I started taking Vitamin C. I read it was water soluble and therefore eliminated from the body, therefore no build-up and not harmful. I inquired about Vitamin B with my radiologist after reading about its benefits--especially to

mastectomy patients on the right breast. The radiologist pooh-pooed the article and its possibilities. I was determined to help myself so I started taking Vitamin B. I had learned through this experience that I was on my own—with almost no help from anyone. But isn't that life?

Most found some degree of ambiguity about the causes of breast cancer and consequences of just about every treatment protocol in popular literature, autobiographies, and primary research literature. All varied on explanations of why one contracted breast cancer and what might best be done about it when it was discovered.

Commonly, when individuals began to grasp that the 'experts' in different disciplines or different locations were ambivalent and/or ambiguous about what was 'best,' frustration and loss of faith in 'medical expertise' would begin to set in. In some cases, these experiences would be transmuted into empowerment as individuals tackled the primary research literature, professional and lay publications, and made their own decisions about what and how much treatment they would receive. Sometimes the expertise of the medical establishment was rejected, either partially or completely, in favour of alternative health strategies. In other cases, individuals became demoralized and depressed and experienced deep grieving related not just to loss of full health but also to loss of assumptions and beliefs in external experts. Above all, there was a quest to learn more about other women who had a similar experience. "*I want to know*" was a phrase frequently heard both in my clinical counselling work and in the narratives of the informants. In this research study, I expect to create further understanding of what it means to be the recipient of a diagnosis of breast cancer by sharing the experiences of the informants.

In summary, with my interpretations of the breast cancer partial-biographies resulting from the ethnographic questioning of 13 women, I aim to weave the external cultural norms about breast cancer together with the informants' experiences in a tapestry resulting in an ethnographic report. My objective is to present the material interpreted in a way that is clearly practical for inclusion in counselling and counsellor training programs. As a research 'outsider,' I want to bring to public light the cultural experiences of what it is like to have breast cancer for each of the 13 informants. As a co-researcher with the informants, I was privileged to be taught by each woman how she constructed her reality. These 13 individuals teach how successes at home and at work pale in significance within the context of struggling with a disease which is perceived as a threat to life. Boundaries and limits set in times of health often became skewed.

A survey review of the literature on breast cancer follows. Studies on breast cancer drugs have been purposefully omitted as there is no consensus on what 'really works' from country to country. Also, drug studies do not contribute to an understanding of the psychosocial aspects of breast cancer treatment. Cancer and stress begin the literature review next.

CHAPTER 2: REVIEW OF THE LITERATURE

Literature: Cancer and Stress

The Hopi had been through some rough times with whites. No matter how hard I tried, understanding the Hopi was difficult at best. Reasoning and Aristotelian logic didn't work. Their way seemed to have been laced with a dogmatic pragmatism. . .

As a newcomer, it was inevitable that I would make mistakes in judgment, behavior, and in the way I was responding, but most of all in my perceptions. Unexpected things would happen and I would be caught unaware of what I had done . . . After a while I became overwhelmed by a feeling that I had been unceremoniously dumped in the middle of two surreal worlds: one Kafkaesque, the other akin to Alice's Wonderland (Hall, 1992, pp. 110-112).

Each informant reported experiences of stress after receiving a diagnosis of breast cancer. Each attempted to understand the diagnosis and prognosis. Each felt varying degrees of being overwhelmed and being dropped into another world. 'Not understanding' produced a lot of stress, many stated. Stress is a multi-dimensional response to changing person-environment relationships, a requirement of adaptation. Quite often, I heard informants state that they just did not understand what the diagnosis or treatment protocol really meant. So, in the absence of meaning, those receiving a diagnosis of cancer adapted to this information in a variety of ways. Clients and informants discovered that they had a variety of needs which were not met, so each attempted to find ways to problem-solve. The women in this study told me that virtually every aspect of their lives was modified as a result of their changed status to a 'person-with-cancer.' Due to the ambiguity surrounding treatment combined with the cultural taboos, understanding appeared to be impaired between the client and just about everyone

in her life, personally and professionally. Stress was the consequence and cornerstone of all that was awry (Mathieson, 1991). The examination of stress became a necessary preliminary for this ethnographic report. When counselling women with breast cancer, I found the women often alluded to major stresses which preceded their diagnoses. It should be noted that groups for women with breast cancer currently include relaxation and stress reduction training, usually at clients' requests.

One recent study (Bunston, 1997), describes the multitude of challenges women must cope with following diagnosis and treatment of breast cancer. Results indicated that 97.6% of the women in the study reported having new needs. Forty-seven percent reported that either their needs were not met or that they required additional help. Barriers to needs resolution included having difficulty coping and/or not knowing how to ask for help or where to seek help.

Ersek (1986) explored and described possible physiological mechanisms linking stress and cancer in research done in the fields of psychology, immunology, and neurophysiology. Experimental evidence was examined, exploring the links among stressors, stress responses, coping styles, neuroendocrine responses, and immunologic alterations. The paper concludes that as different research paradigms are employed by the three fields, methodological difficulties often obstruct data interpretation. The influence of physiological processes of stress on the initiation or progression of the malignancies is also discussed. Clients comment on the precursors and juxtaposition of stress to their diagnosis. Elaine Zyri, an informant, states:

I started on the path of having breast cancer, but I think I got here through stress and not knowing how to cope and not knowing how to deal with stress and not knowing how to ask for my own needs, wants and desires to be fulfilled. I also came from a very brutal dad, and my mom was very busy putting kids' fires out and didn't have time for us, so we were sort of left in limbo.

Humans respond to stress physiologically, expressly through cardiovascular changes directing the body to 'fight or flight.' In receiving a diagnosis of cancer, one can neither flee nor fight physically. However, the life threatening connotations of the stress message causes the body to generally mobilize physiologically. Adrenalin pours into the bloodstream. Many women recount feeling "waves of terror." After her diagnosis, Denise Forest states:

I was so terrorized that every time I would start to fall asleep I would wake up again and be sitting up in bed . . . saying "no, no" and crying and my partner would have to hold me . . . It was awful.

I don't think that probably people that work in that field have any conception of what it is like those first days . . .

The interaction between the person and environment and how stress may affect coping strategies has exciting possibilities for potentially slowing or halting the progression of malignancies (Watson, 1992). Modern stress research was catapulted into public awareness by Hans Selye (1946), a pioneer of stress research, who detailed the physiological stress reaction in 'the General Adaptation Syndrome' (also known as 'a syndrome produced by diverse noxious agents'). Within this biologic stress syndrome, Selye described three phases of stress which lead to loss of ability to adapt, which in turn, leads to death. These phases are: the alarm reaction, the stage of resistance, the stage of exhaustion (with the sequelae of death). In 1974, Selye again pioneered a new era in

stress research: that of looking at eustress, or the positive values of stress. Eustress is described as necessary for motivation to act, to change, and to grow.

In another view of stress and its relationship to illness, Maddi and Kobasa (1984a) examined the dimensions of hardiness, a concept which appears to be correlated with a low illness rate. Kobasa (1979), coined the term 'hardiness' after studying a cohort of male management personnel and finding three factors in individuals which appeared to protect them from illness. The three personality dimensions which emerged are commitment, control, and challenge in both life and work.

Each individual learns to live with or cope with cancer in his or her own way. How individuals construe living or coping with differing diagnoses of cancer has been the object of much research. Recent studies on coping most often reflect examinations of one or more variables selected by the researchers. One variable, for example, is coping. Folkman and Lazarus (1988b) examined coping and identified eight cognitive and behavioural strategies describing what people do under stress. Using this information they designed and implemented the "Ways of Coping Questionnaire," which is currently used in many counselling settings in North America.

In reviewing the literature on stress and coping with cancer, I found little descriptive subjective research on coping skills emerging from cancer patients themselves. Individuals living and working with cancer patients have been asked how they coped. Breast cancer patients themselves had not been asked open questions to describe their experiences in their own words without some sort of direction being given

by the researchers. In this research, ethnographic questions reduce the possibility of researcher bias to a minimum. A recommendation is:

. . . that a cultural interpretation rests on a foundation of carefully collected ethnographic data; and that the quality controls of ethnography--triangulation, contextualization and a non-judgemental orientation--help eliminate the drawback of personal bias (Fetterman (1989, p. 28).

This study uses both contextualization and a non-judgemental orientation together with a form of triangulation, a compilation of the emergent universal themes to minimize bias.

Those who have a diagnosis of breast cancer are adding to our knowledge, informing and teaching others who may benefit from understanding more about how a person with breast cancer experiences the cultural context of her life.

Literature: Cancer and Coping

Each individual learns to live with or cope with life in his or her own way. How individuals construe their lives has been the object of much research (Peavy, 1991).

Cancer studies most often employ quantitative research methodology and reflect examinations of variables selected by researchers (McIntyre, 1988; Roberts, 1992).

Given that random sampling from the population is not possible to select cancer patients, random assignment to experimental and control groups is typically utilized for treatment issues. Many medical professionals tend to design research tools based on their assumptions, experiences, and questions, rather than on the experiences of the clients. An example is the quality of life index designed by nurses for those with cancer (Ferrans, 1990).

When researchers looked at ways in which those with cancer lived or coped, they often resorted to surveys, questionnaires, or on occasion, to case studies. The concepts studied related to the researchers' questions and were rarely directed to query the needs of those studied. The passivity of cancer patients was largely taken for granted. Only recently have there been some qualitative studies which attempt to understand the issues of being a cancer patient from the perspective of the individual(s) concerned (Carter, 1989; Hilton, 1988). The results of 'objective' or quantitative research findings tend to mirror the researchers' ideas and experiences, not cancer clients' ideas and experiences. One example is an investigation to test the association between psychological factors and cancer progression using a repeated measures design (Roberts, 1992); another is a randomized controlled experimental study on the effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival six years later (Fawzy, Fawzy, Hyun, Elashoff, Guthrie, Fahey & Morton, 1993). A study with random assignment to a support group, education group or coping skills training had method problems which limited the interpretation of results (Telch & Telch, 1985).

A recent study by Pikunas (1997) chose a questionnaire to be self-administered by breast cancer patients in addition to a set of nurse-administered "yes/no" questions. Responses indicated that 58.9% of respondents were at risk for clinical anxiety, and 15.8% were at risk for clinical depression. The most frequently noted response was the presence of worry or feelings of hopelessness (63.3%). Concluding remarks in the paper recommended that brief screening at the diagnosis stress point, followed by clinical interviews and psychological interventions would have a distress prevention function.

Another study questioned positive and negative changes in beliefs of cancer patients following victimization and found that active coping was associated with positive belief systems (Collins, Taylor, & Skokan, 1990). Fosket, Lafia, and Rose (1997) used a sample of articles taken from popular American women's magazines from 1913 to 1996 to examine changing cultural meanings and metaphors of breast cancer. Critical discourse analysis was used to study the language used to create metaphoric messages and symbolic meanings about breast cancer in popular media. Analysis over eight decades showed that confusion, contradiction, and parallel messages were embedded in metaphors of hope and fear. Articles have a 'fairy tale' quality which promotes survival and cure as the defined boundaries of breast cancer. Simultaneously, readers are assaulted with fear-provoking discussions that stress risk factors such as diet, exercise, the pill, stress, and alcohol as causes, and personal responsibility as prevention and cure. The authoritatively approved of 'womanly thing to do' is to look beautiful, be courageous, withstand suffering, and protect loved ones. The 'unwomanly thing to do' is noted by the absence of stories about advocacy and action, anger, pain, discouragement, depression, mutilation, fatigue, and death. Military metaphors (i.e., winning the battle in the war on breast cancer, weapons in our chemotherapy arsenal, striking at the enemy within, etc.), adopted by scientific and medical reporting impose a sense of order, control, and progress over a disease whose causes, treatments, and cures continue to be debated world-wide (Fosket et al., 1997).

Literature: Theoretical

Theory papers often outline concepts as scaffolding, to demonstrate ideas held by authors who may or may not be involved in actual research. Callan (1989) outlined a

research framework developed from concepts of Viktor Frankl's (1962) logotherapy and also from recent research in psychosocial oncology that focussed on hope in counselling cancer patients.

Northouse and Wortman (1990) provided a theoretical analysis of four models of helping and coping which focussed on the proportion of responsibility clients should have for the cause or treatment of their cancer. Another paper by Johnson and Lauver (1989) discussed four theories (emotional drive, self-regulation, cognitive appraisal, and self-efficacy) and their limitations as relevant to how cancer clients cope with stressful experiences. Derdarian (1986) discusses theories of coping, appraisal, information seeking, needs, and hierarchy of needs. Cancer clients were asked their needs in relation to harms, threats, and resources. Few differences were noted by gender, age and stage of cancer.

Dow (1991) discussed the growing phenomenon of surviving cancer and recommends that nurses be aware of the specialized needs of this population. Comments on health care policy, research, and nursing practice regarding cancer survivors are also presented. There are qualitative studies examining the issues of those who work and support cancer patients, such as nurses (Taerk, 1983). Other studies have focussed on the impact of cancer on spouses/mates and have found the most frequent results were anxiety and depression (Howell, 1986).

None of the theory papers in cancer research propose asking the cancer clients for their experiences, thoughts, and ideas, and how these might be used to enhance health service, client counselling or client education. This study addresses this oversight by

using ethnographic methodology. Cancer clients speak directly to me, the naive researcher, and to the readers of this ethnography, to tell us what living with a diagnosis of cancer is like in response to open-ended ethnographic questions. Cultural themes which emerge from the informants' spoken data are organized and synthesized to inform and drive theory on how to enhance counselling with cancer clients and their families. Locating this ethnographic report within the context of existing knowledge and research facilitates the practical application of data to real life counselling and counsellor training.

Literature: Family Members and Support Workers

There has been an increase in the number of qualitative studies on cancer and coping in the last decade. Many of the studies, though, have focussed on patients and family members and how they live with cancer (Northouse, 1989). For example, Woods, Lewis, and Ellison (1989) describe what it is like to live with the person who has a diagnosis of cancer, from the perspective of the family. Martens and Davies (1990) interviewed seven cancer clients living with advanced cancer at home and also interviewed their spouses; qualitative analysis of the audiotape interviews was implemented to explore what resources were used by client and spouse. In this same vein, questions have been asked of both cancer patient and spouse, either examining concerns of both partners (Gotay, 1984), or examining the meaning of 'quality of life' to cancer patients (Padilla, Ferrell, Grant & Rhiner, 1990). For example, Gotay (1984) conducted semi-structured interviews with cancer clients and their mates about major concerns. Those with advanced stage cancer were more likely to discuss their fear of cancer with others, while mates were more likely to cope with their fears through action. Stolar

(1982) interviewed 90 women who had mastectomies to discover how they dealt with the diagnosis and treatment of breast cancer. Results showed that stress and distress are experienced by both clients and families. The crucial factor for recovery is an available and active support system, which may include extended family, friends, and medical staff. Hart (1986) explored the relative stresses of one family member plus one other significant other (another family member, a close friend, etc.) for 25 cancer clients. No significant difference emerged between the level of stress expressed by family and non-family significant other.

Lewis and Deal (1995) combine family research with autobiographical interviews in their study of 15 married couples' experience with breast cancer recurrence. Structured interviews were held in the couples' homes using open-ended interview schedules together with two standardized questionnaires. Results indicated that maintaining a balanced life involved four major processes: managing the daily realities of the women's illness, surviving, healing, and preparing for death. Overall, the couples worked to keep breast cancer in the background, not foreground. Not surprisingly, one or both members of 60 percent of the couples scored above the mean either on depressed mood or on the marital adjustment scale.

Research on support workers is also available. Nurses working with those who have a diagnosis of cancer were surveyed to identify the most difficult patient care problems. Top ranked issues related to personally experienced emotional responses to cancer clients and to physical care issues such as nutrition and pain management (Bramwell, 1989).

Literature: Autobiographical Accounts

*Received: One breast, with skin and nipple, fresh,
Some twenty lymph nodes and a pad of fat
By the pathology lab. A pound of flesh?
They'll culture it, and then -- and after that?
Try not to see, or try to cauterize
The image in the shadows of the mind:
My breast, blue-veined, that yielded to your hand;
Stack belching tainted smoke into the skies.
Drink up the cocktail -- vanity laced with shame--
What's one lost breast beside a rescued life?
I've neither God nor my own self to blame,
And I'm -- yes, thankful for the healing knife.
And yet -- and yet -- beneath this blousy tunic
I know myself half woman and half eunuch.*
(Mumford, 1986, p. 28).

Autobiographical accounts of coping with cancer are described by both those in the medical profession and lay-persons. A psychiatrist, Stoudemire (1983), and a therapist, Alexander (1989), offer both a description and an analysis of their experiences with cancer. Another example of this genre is Mack's (1984) account in which he is self-described as a successful 50-year-old surgeon, hard-driving, competitive, and subject to all the pressures of a busy practice. He describes all of the personal stresses, including the breakdown of his marriage, which preceded his diagnosis of lung cancer. Twice he thought treatments had eradicated his cancer. Scrupulously, he followed all the conventional medical therapies available. He also employed some alternative therapies, such as visualisation and relaxation, and worked regularly with a personal counsellor. Ironically, he noted that he had to face pain and the possibility of death before learning the 'purpose of being, and how best to live a rewarding life.' Statistically, he knew there

was no likelihood of his surviving cancer with widespread metastases, but eventually he came to a peaceful acceptance of his 'lessons learned from living with cancer.'

Some provocative accounts of breast cancer are emerging. Accounts from individuals such as Ferguson (1990) and Wadler (1992) focus on the authors' experiences and thoughts about their breast cancer treatment and current remission. Powerful depictions of two Canadian women's varied journeys with a diagnosis of breast cancer are Williams (1993) and MacPhee (1994). Hart (1993) and Wittman (1993) also authored books describing personal experiences with breast cancer.

There are other individual voices of cancer clients representing unique issues, experiences, and lessons learned from living with cancer, including Campbell (1984), Fiore (1984), and Wilbur (1988). Autobiographical accounts may also focus on coping techniques such as Cousins' (1976) strategy of incorporating humour into his recovery. Humour as a strategy continues as his memorial, in that most large oncology treatment services include a Humour Room, or minimally, a collection of humorous video and audiotapes.

Literature: Case Studies

Case studies are often employed by clinical researchers to describe the cancer experience of a single person or a small number of individuals. For instance, Roud (1987) examined the psychosocial variables associated with the exceptional survival of nine patients who had advanced malignant disease. The individuals believed there was a direct relationship between receiving the diagnosis of cancer and their intense desire to live; they assumed responsibility for all aspects of their lives and formed a strong bond with

their physician. Another study by Roberts, Elkins, Baile and Cox (1989) examined the psychosocial impact of breast cancer. The researchers interviewed 50 breast cancer clients in remission and 50 healthy individuals as controls and found no significant differences between clients and controls on the Profile of Mood States scale.

A recent psychobiological perspective study by Stanton (1992) explored the possibility that biological pathways might be a means of communicating constructive or destructive images from the areas of the brain that mediate emotion and memory to peripheral area cells and so contribute to the onset of cancer. In-depth psychological evaluations were done on eight cancer clients and case studies were presented.

Literature: Surveys

Surveys represent a heavily used quantitative research technique as they are straightforward to design and easy to administer. Grimm (1989) in a cross-sectional survey design examined trait and state levels for hope, and found that sex, religion, and marital status were more significant discriminators of hope levels than illness factors. Gotcher and Edwards (1990) examined the coping strategies of cancer patients using a survey tool which asked clients to identify relationships between actual communications and imagined interactions. They found that imagined communications reflected cognitive coping strategies with cancer and were related to actual communications.

Literature: Questionnaires

Coping questionnaires abound in the literature since questionnaires are easily administered by medical staff in a medical setting. Questionnaire results are generally quantified as yes/no questions or in scales such as the Likert Scale, which measure things

such as 'Most to Least of item X', with incremental values indicating the degree. One coping questionnaire by Padila et al. (1990) asked cancer patients about the meaning of quality of life. Another study by Collins et al. (1990) asked cancer patients questions about positive and negative changes in beliefs following victimization. The results of this questionnaire found that active coping was associated with positive belief systems (Collins et al., 1990).

Hopkins (1986) developed the Information Preference Questionnaire, which measures both how well a patient was adapting to the chemotherapy treatment experience, and how much information the patient was seeking with respect to treatment. No significant relationships were identified between information-seeking and the adaptational outcome measures of mood states and level of functioning. The Meaning of Illness Questionnaire, developed by Brown, Bryne, Roberts, Fitch, Corey, and Arpin (1988) tested the above questionnaire for reliability and validity. The questionnaire demonstrated reliability and validity in measuring a variety of concurrent yet divergent meanings that can be given to an illness for three chronically ill populations, those with mixed cancer, rheumatological, and gastroenterological disorders.

Edwards, Cooper, Pearl, and de Paredes (1990) used questionnaires to review the link between breast cancer and psychosocial variables. The variables among 1,025 women with and without breast cancer included life events, coping, Type A behaviour patterns, and availability of social support. They found little to support links. A study by Waxler-Morrison, Hislop, Mears, and Kan (1991) examined the relationship between 133 women's social contexts at the time of diagnosis and their chances of surviving cancer

four years later. Questionnaires were mailed to patients from hospital soon after diagnosis. Results from the self-administered questions indicated that the social context of the client, particularly of friendship and work outside the home, were statistically important for survival.

Tests as questionnaires are also employed to examine how those with a diagnosis of cancer function. Starck (1983) used a test of meaning in suffering (MIST) and the results demonstrated that most subjects believed that suffering had meaning and that some good came out of it.

Literature: Other Research Methods

There are other research methods which pertain to living with and/or coping with cancer. These include: Needs Assessments which outline ways to live and cope with cancer (Grahn & Johnson, 1990); Coping Scales which examine the relationship between hope and how one copes with cancer (Herth, 1989); the design of educational programs created to provide opportunities for the cancer patient to learn to cope with cancer (Diekmann, 1989; Fredette, 1990; Pritzker, 1988); and the development of a Quality of Life Index for patients with cancer (Ferrans, 1990).

A national telephone interview study was done by Eisenberg, Kessler, Foster, Norlock, Calkins and Delbanco (1993) exploring the use of unconventional medicine in the United States. The researchers conducted telephone interviews with 1539 adults in a national sample of adults 18 years or older in 1990. Unconventional therapies were frequently used by those with cancer. The conclusions stated that doctors are encouraged to ask patients about use of unconventional therapies since the frequency of use is far

higher than anticipated. Individuals spent approximately 13 billion dollars on unconventional therapies in 1990, approximately 10 billion of which was spent out of pocket. Seventy-two per cent of respondents did not inform their medical doctors of their visits to providers of unconventional therapies.

Literature: Phenomenological Studies

Phenomenological studies investigate the lived experience of a small group of individuals on specific researcher-defined topics. In contrast, ethnographic studies have as their mandate to provide participant-driven data, actively implementing strategies to minimize researcher bias. Several phenomenological studies have asked cancer patients about certain aspects of their experience with cancer. For instance, Shaw (1988) employed a phenomenological study designed to explore the ‘experiences of women during initial treatment for breast cancer and to assess the meaning of those experiences.’ Results showed that cancer-related events, coping strategies, and the support of others were major factors that contributed to women’s experiences. Moch (1988) asked women with breast cancer to describe their experiences using an existential-phenomenological methodology ‘with a focus on person-environment interaction patterning’ in order to explicate the view of health in illness.

Hilton (1988) examined the ‘phenomenon of uncertainty’ in women with breast cancer and discovered that primarily negative emotions were associated with uncertainty, and positive emotions with sureness. Carter (1989) used a phenomenological interpretive approach to ‘collect and analyse the survival stories’ of 25 women (survival periods of 5 to 26 years) with breast cancer. Many of the participants reported that the cancer

experience left them with a clearer sense of Self, deeper gratitude for life, and strength and confidence in their ability to manage life crises. Emphasis on survival and remission was predominant in this report.

Kesselring (1990) employed 48 interviews in an phenomenological study of 18 women who 'underwent chemotherapy for breast cancer.' Grounded theory methodology was used for analysis. Embodied experiences and the experienced body are described as 1) the shaper of self and world; 2) identity when subjugated to medical interventions; 3) the body as it was conceptualized. It was suggested that this study's findings might enhance nursing's growing interest in phenomenological approaches to caring and contribute to understanding of embodied illness experience.

A descriptive cross-sectional study by Taylor (1992) examined the 'search for meaning among persons living with recurrent cancer.' Three groups emerged in this research: those who reconcile, those who remonstrate, and those who resign themselves to the meaning of their cancer. The findings recommend that nurses provide support for those who struggle with the search for meaning. Dunaway, Hueston, and Clevinger, (1995) investigated the cultural factors influencing patient adjustment to chronic illness. Ten rural women with a 12-36 month prior diagnosis were questioned using a long-interview qualitative research format. Results indicated that these women with life-threatening cancer were dissatisfied with patient-physician communication. The clients expressed a greater need for information and collaborative decision-making.

Mathews, Lannin, and Mitchell (1994) analysed 'in-depth interviews with 26 black women from rural North Carolina who had advanced breast disease.' It was

reported that the women did not want biomedical explanations; instead, they found meaning in their experience from their own perspective of health which emphasized balance in the blood and popular American cultural ideas about cancer. Their narratives provided information about the process of adapting personal experience to pre-existing cultural models.

Literature: Denial

Matt et al. (1988) suggest that in some situations denial may be a useful coping strategy. They define denial and coping in general and they review the potentially positive functions of denial and potential negative consequences. They advise caution in assessing denial and its utilization by the cancer client in order to determine the advantages and disadvantages. Denial of cancer can be adaptive or maladaptive. An exploratory study by Wool and Goldberg (1986) of 15 cancer patients outlined four kinds of denial: 1) denial of the physical aspects of cancer; 2) denial of the diagnosis; 3) denial of the implications of cancer; and 4) denial of affect. They suggested that denial be looked at as health-seeking behaviour and that social support be given to reduce or modify the denial which results in maladaptive behaviours.

Literature: Personal Meaning

For many cancer patients, the personal meaning of a breast cancer diagnosis is as a serious threat to life itself, precisely because there are so many unknowns. However, there are also many fears surrounding the symptoms and consequences of the illness. Research discussing 'psychological morbidity' of cancer clients (Mathieson, 1991; Moorey & Greer, 1989) includes many features of psychiatric illnesses such as

depression, anxiety, sleep disturbance, and weight loss. Morris, Greer and White (1977) found that anxiety, depression and sexual problems are experienced by many following mastectomy. Twenty to 25 percent of clients may be clinically depressed for up to 12 months following surgery.

Counsellors working with cancer clients often find that both physical and psychological issues appear in concert. Cognitive and behavioural counselling methods predominate in many medical settings serving cancer patients. An eclectic counselling approach, however, is generally considered facilitative since multiple multi-layered issues often surface in counselling. Clients often face existential issues for the first time in what they deem this new threat to survival. Freud states that it is:

. . . impossible to imagine our own death; and whenever we attempt to do so we can perceive that we are in fact still present as spectators (Freud, 1953, p. 17).

The threat to self from cancer can be processed in several ways, either as a challenge which might turn to triumph, as a threat which could devastate, as damage which has already happened, or, the threat may be denied. The appraisal, or the individual meaning cancer has for each individual, is an indication of how the person is coping with the stress of his or her cancer diagnosis. Lazarus and Folkman (1984) suggest that the role of appraisal in stressful situations is a critical aspect to coping. Counselling cancer clients often begins with the individual's statement of what personal meaning the diagnosis of cancer has for him or her.

Fighting cancer must come to mean more than excising a tumour and focusing the latest weapons on the metastases. It must include a recognition, by both the medical professionals and the patient, that the patient's mind and body are powerful factors in this fight. Failure to use these potential allies can mean losing

them to the 'enemy' through patient resistance to treatment, depression and loss of will to live. Effective cancer therapy must treat the healthy portion of the patient's body and psyche as well as combat the diseased cells (Fiore, 1979, p. 12).

Cancer poses a threat of death. It also poses questions about body image and self image. The symptoms, treatment and negative consequences of cancer are linked with suffering, debilitation, disfigurement, and changes. These changes may be in mental and physical abilities, in personal and social roles, and in appearance. These changes may all be considered threats to an individual's personal domain (Moorey & Greer, 1989). Beck (1976) states that the individual's emotional response depends on how he or she cognitively perceives the events as they relate to their world. For example, how the experiences add to, subtract from, endanger, or affect the individual proceeds from individual cognitive processing.

Four common emotional reactions to receiving a diagnosis of cancer are: anxiety, anger, guilt, and depression, separately or in any combination (Silberfarb & Greer, 1982). Inevitably, clients experience these reactions as stress, as threats to their personal domains.

Literature: Counselling

Counselling cancer patients always involves elements of working with the stress which accompanies the diagnosis and treatment protocol (Greer & Morris, 1974). Stress in cancer often is experienced simultaneously as negative or incapacitating and as a positive motivator to action. Mathieson and Stam (1991) examined the issues of who needs counselling most and what therapy ought to be provided when. They suggest that since a diagnosis of cancer is almost universally considered stressful, individuals who

attempt to renegotiate a new personal identity as someone-with-cancer require maximum support. As well, they conclude that the most effective counselling will involve a focus on the person, not on the disease.

Many strategies for counselling cancer clients are disseminated through groups. Some research studies of group counselling include those of Cunningham (1988) and Cunningham, Lockwood, and Cunningham (1991). These studies evaluate differences between groups which have counselling strategies and groups which do not (Cunningham & Tocco, 1989). The results indicate that there are no significant differences in longevity between the two groups, but counselling strategies do appear to improve the quality of life of clients. Speigal (1989) and Speigal, Bloom, Kremer & Gotteil (1989) demonstrated both a positive difference in survival time and in quality of life as measured by significant reductions in mood disturbance and in the reactive component of pain for those in group therapy. Group dynamics, education, and social support are considered factors in the positive differences.

A pilot group counselling project for cancer clients was undertaken in an acute general hospital (Wood, Milligan, Christ & Liff, 1978). Evaluation revealed that the group experience was useful and helpful. The study concluded that having separate groups for cancer clients and family members was important, as was providing support for therapists to share their feelings of frustrations and feelings of discouragement.

There are many styles of counselling cancer clients. Often the method is tailored to the specific needs of cancer clients, such as the telephone counselling program at the Memorial Sloane-Kettering Cancer Centre in New York (Mermelstein, 1991). Other

styles may respond to cancer clients' need for support and education. One group formed the basis of a study by Pritzker (1988) to develop, implement, and formatively evaluate a psycho-educational treatment program for post-mastectomy women. The primary objective of the program was empowering participants to develop methods of meeting their informational and support needs by increasing their ability to use effective coping strategies.

Another study by Fredette (1990) used various theories including the stage theory of dying by Kubler-Ross (1969) to develop an educational model for cancer clients. Fredette suggested that the use of this model can improve teaching effectiveness with clients and could also be used to teach students about incorporating stages of dying and grief, some of which are shock and numbness, denial and withdrawal, bargaining, acknowledgement, pain and acceptance, and adaptation and renewal into their counselling model.

Strategies such as meditation, visualization, and relaxation are frequently used by those counselling cancer clients across the spectra of all counselling theories (Simonton, Simonton and Creighton, 1978). Since stress, anxiety, and depression in cancer clients may significantly compromise the quality of life, stress reduction is a desirable goal. The results of a relaxation therapy program for those undergoing radiation suggests that relaxation training substantially reduced tension, depression, anger, and fatigue (Decker & Cline, 1992).

Studies comparing drug therapy with relaxation training (Holland et al., 1989) demonstrate that both study groups showed significant drop in anxiety and depression.

The drug group showed a slight advantage, lowering depression and overall symptoms, earlier. Many counsellors use cognitive-behavioural methods (Meichenbaum & Turk, 1976; Moorey & Greer, 1989) to challenge the cognitions and negative appraisals of cancer that many cancer clients carry, each from her own cultural background.

There are also many survivor self-help groups in existence, some of which form the basis of both the Canadian and American Cancer Society's 'I Can Cope' programs. These programs employ volunteer survivors of cancer experiences to share and teach about such issues as self-esteem, health and wellness, personal attitudes, self-education, sexuality, and resource-finding (Johnson & Klein, 1988). Books such as Jevne and Levitan's (1989) No Time for Nonsense: Self-Help for the Seriously Ill teaches strategies for self-help to those who are ill and to their families.

An ethnographic method of research was used to look at the 'functions of a breast cancer support group, as perceived by the participants' (Cope, 1995). The group consisted of 15 women, diagnosed with breast cancer within a time-span of 2 weeks to 7 years previously, and a professional group facilitator. Content analysis was done on taped recordings of 10 group meetings plus two interviews with two key informants. Three functions of the group emerged: exchanging information; sharing the illness experience; and providing strength. The author notes that as the rate of breast cancer is rising steadily, it is essential that nurses and medical practitioners identify sources of social support for women

Conclusion

Until the last decade, most research on those diagnosed with cancer employed quantitative empirical research protocols (Holland & Rolland, 1989). Until the 1970s, research in the area of psychosocial oncology focussed mainly on hypothesis testing. This research involved identifying and defining medical clinical problems in cancer and then developing hypotheses about clinical interventions. Subsequent studies investigated development and testing of assessment instruments and procedures (Cella, Jacobsen & Lesko, 1989).

The Handbook of Psycho-oncology, Psychological Care of the Patient with Cancer, edited by Holland and Rolland in 1989, ends with a chapter on Research Methods (Cella et al., 1989) and does not even allude to qualitative studies. Qualitative studies, or those asking the patients for their point of view or asking for client input into research were not a reality then and are only slowly becoming more acceptable. When and if researchers chose to look at ways in which those with cancer lived or coped, they often utilized clinical studies, surveys, questionnaires, or, on occasion, case studies. The concepts studied in these cancer patient studies served to meet a biased requirement of the researcher, rather than explore the world of the cancer patient with respect to the patient's requirements. The methodology was generally postulated on some form of hypothesis testing. As illustrated above, more recent qualitative phenomenological studies explore the patient's experiences from a direction chosen by the researcher(s).

This study fills a niche in cancer research and breast cancer counselling by using ethnography which attempts to understand the issues of being a cancer client from the

perspective of the individual(s) concerned, with a minimum of researcher bias. The research focus in ethnography is on the language used by informants to describe their personal experience of living within their 'culture,' the culture of being a woman with breast cancer. Thirteen women have been asked to share their daily experiences of living with a diagnosis of cancer. I have listened, recorded what each participant had to say, and then analysed the content of the interviews. This research was limited to the experiences the informants were able to transmit in words, in a person-to-person interview with me, the researcher. Through the language of 13 women who are facing the multiple challenges of living with a diagnosis of breast cancer, I have been taught about the possibility of new ways of counselling others in the same predicament.

This is the battle of *faith*, battling, madly, if you will, for possibility, because possibility is the only salvation. When someone faints, we call for water, eau de Cologne, smelling salts; but when someone wants to despair, then the word is: Get possibility, get possibility, possibility is the only salvation. A possibility-- then the person in despair breathes again, he revives again, for without possibility a person seems unable to breathe (Kierkegaard [1848], 1990, p. 38-39).

The review of the literature presented above surveys the current breast cancer research excluding quantitative studies. This general overview indicates that a cross-sectional ethnography would add useful information to the body of research knowledge extant. One intent of using the ethnographic questioning method is to have an accurate picture of the culture under study reproduced in the final report. Although one cannot overly generalize from the data in the ethnographic report, common universal themes and connected issues emerge. These common themes have face validity and as such tend to be accepted by the reader as factual (Visweswaran, 1994). The universal themes and

connected issues in the final ethnographic report act as sign posts to direct further research.

CHAPTER 3: METHODOLOGY

Cross-sectional Ethnography and Ethnographic questioning

To understand what it is like to live with a breast cancer diagnosis, it is essential to go directly to those involved and ask them about their lives:

If it is our serious purpose to understand the thoughts of a people the whole analysis of experience must be based upon their concepts, not ours (Boaz, 1943, p. 11, cited in Spradley, 1979, p. 24).

An ethnographic methodology will be used to interview participants. The social research style that emphasizes encountering alien worlds and making sense of them is called ethnography, or “folk description.” Ethnographers set out to show how social action in one world makes sense from the point of view of another (Agar, 1986, p. 12).

Living amid disease is universal to the human condition. Each culture has norms governing such issues as power, gender, health, and illness. Cross-sectional ethnographies examine culture in context for a cross-section of members of a culture or subculture. The choice of the ethnographic interview was selected specifically to ask those with breast cancer how they experience and interpret their world in order that we may more clearly understand ‘the culture of the breast cancer client’ from an insider’s point of view. There have been no cross-sectional ethnographic studies exploring the world of those diagnosed with breast cancer in a comprehensive literature review of five disciplines: Medicine, Nursing, Education, Social Work, and Psychology. No ethnographies were found which focussed solely on the points of view of those living with breast cancer. Further review revealed no studies which asked the fundamental question: What is it like to be someone who has been diagnosed with breast cancer? The decision to ask breast cancer patients

themselves about how they experience their lives emerged from my work counselling at the B.C. Cancer Agency in Victoria, British Columbia, and from facilitating groups of patients diagnosed with cancer at the Princess Margaret Cancer Hospital, a regional cancer hospital in Toronto, Ontario. Individual clients complained bitterly that they were rarely, if ever, consulted or asked about what they experienced and what their individual needs were. They often stated that they felt the context of their lives had been stripped away and that they were reduced to an object: a decontextualized medical diagnosis-and-treatment-protocol-recipient.

For the purpose of this study, the ethnographic questioning method of Spradley (1979) was an appropriate interviewing method, as it would inform from the descriptive words of women themselves the issues which accompany a shift from one cultural status, that of health, to another, that of having a diagnosis of breast cancer. This method also illustrates the cultural meaning of having breast cancer as explicated by 13 informants. The ethnographic questioning method reduces the researcher's bias and increases the researcher's awareness of her ethnocentricity vis-à-vis this research.

Because the goal of ethnography research is to understand the culture, patterns, and meanings of the world in which an informant lives, credibility exists when the researcher produces an ethnographic report which 'rings true' for those interviewed. Thirteen informants, all of whom have been diagnosed with breast cancer, were selected to be interviewed across the widest possible continuum of age, race, diagnoses, treatments, and experiences (See Appendix F). By definition of their diagnosis they are representatives of the breast cancer population. After analysing the data collected from

each interview, the researcher clarifies the results with each informant for accuracy. The goal of this research is to discover the meaning in the individual's experiences of living with breast cancer. It is important that this information be shared and these meanings used to inform those living and working with, and/or counselling those with breast cancer. It is my responsibility to translate individual narratives so that an overall report emerges without losing any of the original meaning and intent.

People everywhere learn their culture by observing people, listening to them, and then making inferences. The ethnographer employs this same process of going beyond what is seen and heard to infer what people know. It involves reasoning from evidence (what we perceive) or from premises (what we assume) . . . The ethnographer must then make inferences about what people know by listening carefully to what they say, by observing their behavior, and by studying artifacts and their use. (Spradley, 1979, pp. 8-9).

Ethnography attempts to capture the basic meaning of human experience by entering the world of the informants. This cross-sectional ethnography research method revolves around the attempt by the researcher to grasp the meanings inherent in the world lived in by the informant. The research goal is to understand and interpret this world by listening carefully to the informants' answers to the question: "What is your experience of living with breast cancer?". In this cross-sectional ethnography, the researcher focusses on language. It is the language, the words, phrases, images and metaphors of the informants which shapes the research and illuminates each individual woman's experience. The dialogal process between the informant (the teacher) and the researcher (the student) explores and reveals the descriptive details about living with a diagnosis of cancer. Language is made up of phonemes, or units of significant sounds. Language also creates meaning. The researcher must work in two languages, hers and the informant's, to

ensure the informant's meanings are transferred directly and clearly in the ethnographic report.

The social research style that emphasizes encountering alien worlds and making sense of them is called ethnography, or "folk description." Ethnographers set out to show how social action in one world makes sense from the point of view of another. (Agar, 1986, p. 12)

The two main tasks of ethnography are discovery and description. The ethnographer's interest is in first discovering or illuminating the informant's cultural reality just as it is. Then it is the ethnographer's work to provide a linguistic description of that culture in such a way that those who know nothing of the culture under investigation may learn and understand that culture, without prejudice. The researcher uses descriptive language to illuminate the informants' words as they emerge in themes, images, and interpretations.

The Research Process: Inquiry

The ethnographic interview, in this research, takes place at a location chosen by the individual participants and is designed to respond to the needs or requirements of the participant. Thus the informant is in control of the time, place, duration of the interview, and has the option to pace the interview, stop, start again, or terminate the interview at any time. Because of the potential physical limitations of the informant(s) with breast cancer, I was available for multiple short interviews rather than one or two long ones. A number of short interviews ensured that informants had complete control over the opportunities to rest or stop as often as they required. The researcher listens, records what the participant has to say, and then analyses the content of the interview for domains and

themes. Ethnographic research is limited to the experiences the participants are able to transmit in words in a person-to-person interview with the researcher.

This study is concerned with illustrating and illuminating the essentials of the life-world of those diagnosed with breast cancer by learning about their actions, behaviours, roles, beliefs, and values as experienced and described by them in the language of their 'culture.' Each of 13 individuals with a diagnosis of breast cancer or with breast cancer in remission was asked to describe how she experiences living with a diagnosis of breast cancer. The answers contribute to the understanding and knowledge of those who counsel, live, and work with those diagnosed with cancer. Learning from others is the hallmark of qualitative inquiry and this personal learning cultivates our inherent curiosity (Patton, 1990). This research will not only teach others, but also will generate both theory and practical information:

The purpose of basic academic work is to generate theory and discover truth, that is knowledge for the sake of knowledge. The purpose of applied research and evaluation is to inform action, enhance decision making and apply knowledge to solve human and societal problems . . . it is judged by its usefulness in making human actions and interventions more effective . . . (Patton, 1990).

The Research Process: Finding the Women

In seeking candidates for this research, I used several sources on Vancouver Island, in Victoria, British Columbia (B.C.), in Vancouver, B.C., and in Toronto, Ontario. Advertising in local newspapers, placing signs in hospitals in the cities of Victoria, Vancouver, and Toronto, presenting talks at agencies and conferences where breast cancer issues were salient, and sharing by word of mouth--all resulted in calls from

women who had breast cancer. Signs were posted in three hospitals, the Princess Margaret Cancer Hospital in Toronto, Ontario, the Vancouver Cancer Clinic in Vancouver, and the Vancouver Island Cancer Clinic in Victoria, and at two universities, the University of Victoria, (Victoria), and the University of British Columbia (Vancouver).

I spoke about my research project at the B.C. Breast Cancer Foundation Breakfast in October, 1994, in downtown Vancouver. The audience of over 1,000 people consisted largely of breast cancer survivors and medical personnel and many asked me for a copy of the flyer describing my research project (Appendix B). As well, I advertised in local newspapers in Victoria, including specialty newsletters such as the Victoria Sexual Assault Newsletter and the Vancouver Island Lesbian Newsletter. The Vancouver Island Breast Cancer Foundation called and asked for information and I sent them out a packet of flyers for distribution. Word of mouth was passed by all my colleagues, personal and professional, in Victoria and Vancouver, and in Toronto.

The notice asked for participants to take part in a research project which would contribute to opening discussion and reducing silence from those with a diagnosis of breast cancer. One West Coast resource which produced over 40 calls was the Breast Cancer Foundation of British Columbia, from both Victoria and Vancouver branches. Individuals at the Foundation in both locations invited me to their meetings and asked for copies of the research description. Approximately 60 calls asking for information were received.

Selection of candidates was based on physical limitations such as distance, time available, the researcher's interest in interviewing as wide a range of experiences and backgrounds as possible for the greatest variability, and informant interest and availability. Thirteen informants were selected and agreed to participate in the ethnographic interviews.

The Research Process: Initial Contact and Entering the Field

. . . the 'interviewer' constitutes a special kind of stranger in our society, one who can ask about many personal matters without being perceived as breaching another's right to privacy (Schwartz & Jacobs, 1979, p. 63).

Anthropologists refer to the first part of the first meeting with an informant as 'entering the field.' It is imperative that the initial meeting be as nonintrusive as possible. Friendly conversation occurs initially in the interview (Spradley, 1979). If I, as the researcher, am comfortable in my role, and am genuinely interested in each informant, and gentle in my approach and manner, then the subsequent tasks of establishing trust and creating a mutually rewarding relationship with every informant are accomplished.

After prospective informants had been obtained, I contacted each individual by telephone and asked her if she was willing to participate in the study. The purpose and goals of the study were explained to each individual on the telephone and later, in person. Affiliation with the University of Victoria was discussed for the purpose of credibility. Interviews were arranged in a mutually agreed upon time and place.

The informant's privacy and confidentiality was preserved in the consent form (see Appendix C), and confidentiality and anonymity were guaranteed. The participants were informed that they could end the interview process at any time without explanation.

The consent form was reviewed and signed during the initial stages of the first meeting before the interview. In one case the consent form was discussed initially, then signed later.

It was explained to each informant that I am a neophyte who is interested in learning about the informant's culture and I would be a 'learner' during the interview. The informant was invited to teach me, the researcher, about her expertise with the experience of cancer during the research interview. Thirteen informants who had been diagnosed with breast cancer, several of whom were in breast cancer remission, were asked how they perceived their world. Data, collected in the form of dialogue between the informant and researcher, was transcribed verbatim from the taped conversations with each informant and supplemented from notes taken before, during, and after each interview by the researcher. I then wrote the ethnographic report of my understanding of how those diagnosed with breast cancer live their lives utilizing the above data.

The Research Process: Pilot Interview

Two pilot studies were held and these practice runs were useful in preparing effective questions. Volunteer participants, drawn from a Graduate Studies Qualitative Research class discussed, then answered some questions prepared as a preliminary pilot. These responses and discussion were useful in designing a pilot interview with an individual who was chronically ill.

A pilot interview with one patient was then held. The opening question was: "Can you give me a general picture of what it is like to be living with chronic illness?" This

invited the informant to share her lived experience with me and assisted me with the shaping of further questions. Confidentiality and anonymity were guaranteed.

The Research Process: Interviews with Informants

The next phase of research was arranging meeting times for formal interviews with all 13 informants. Interviews took place in a venue of the informant's choosing to reduce strangeness and formality and to maximize each informant's comfort.

An advance interview guide of ethnographic questions was prepared to maintain the connection to task. I immersed myself in the lived experience of the informant and listened with care. Together with each informant, I stayed alert to meanings described in the informant's lived experience.

Sample Ethnographic Questions

There are many different categories of ethnographic questions. Examples of some ethnographic questions used in this study and the categories they fall under follow:

- a) Descriptive: "What is it like living with breast cancer?" or "Could you describe a typical day in your life since you were diagnosed with breast cancer?"
- b) Grand tour: "Can you start at the beginning with your breast cancer diagnosis and describe everything as it happened for you?" or "Would you tell me what the personal meaning of your breast cancer experience is for you at this time?"
- c) Guided grand tour: "The next time you go for treatment would you take me along and show me what it is like?"
- d) Specific grand tour: "Could you give me a metaphor to describe what happens when you go for treatment which tells how you feel throughout?"
- e) Mini tour: "Could you tell me what it is like as you receive your treatment?" or "Could you tell me through imagery what it is like for you to go for treatment?"

- f) Example questions: “Can you give me some specific instances of what it is like when your are receiving treatment?”
- g) Experience questions: “Can you recall any interesting experiences you have since your diagnosis of breast cancer?” or “Can you recall your experiences of feelings or moods during the process after your diagnosis?” or “Do you recall images or colours attached to some of your experiences since you received the diagnosis of cancer?”
- h) Structural: “What are the different kinds of therapies recommended by your doctor?”
- I) Contrast: “What is the difference between radiation therapy and chemotherapy for you?” or “What is the difference between how you experience life before and after this diagnosis?”

Analysis

Following transcription of the interview tapes, I returned a typed copy of the interview to each informant for her amendments. I collected the revised texts, and the transcripts were subjected to a domain analysis (See Figures 1 & 2), (Spradley, 1979). For every interview, I subjected the specific emergent topics to detailed analysis. After the themes which illuminated the phenomena under study were isolated, I summarized the findings in written text. Direct quotations of the informants are presented in Chapter 4.

Assumptions of the Study

This research addresses aspects of verbal interactions with breast cancer patients by examining the words from the situation of the individual breast cancer informant within the larger culture (Thorne, 1991). In any research study using ethnographic questions, the winding uphill path to knowledge begins with the interaction of researcher and informant. All previous assumptions and preconceptions related to the phenomena in

the study are to be 'suspended in disbelief.' The act of 'observing, noting and packing away my beliefs before beginning the research interviews (Spradley, 1979) goes a long way toward ensuring that I 'bracket' my own baggage of value-laden systems to the greatest extent possible. A major assumption of the study is that I am able to objectively interact with the informants by bracketing my subjective reality. I did this by recording my thoughts in my ethnographer's journal and checking with my colleagues. It is also assumed that the informants are able, through the ethnographic interview method, to teach the naive researcher about what it is like to live in their world.

Another assumption is that consistency from informants in ethnographic research is not necessary nor desired. Individuals with life-threatening illness do have mood swings and different levels of physical, emotional, and psychological well-being. Whatever they talk about in describing their experience is valid. Giving as much control as possible to the interviewee reduced my role to listening with full attention to the informant. It was impossible for the individuals to verbalize all their experiences, occasionally causing them to become emotional or withdrawn during the interview. My responsibility extended to being with the participant as fully as possible and to debrief at the end of the interview for closure for the informant and to be available for telephone conversation when the clients wanted to check something out. Six clients did follow-up calls and letters. I responded to all, with additional information of the names of available counsellors should the informants wish to work on any of the issues which arose.

Another assumption is that the information resulting from this study will be of value to those counselling, educating, working, and living with breast cancer patients.

The research on stress, coping, and cancer is in such an early stage that it is essential now to include the voices of those directly concerned. The results of this research, the themes, ideas, and images which emerge from the dialogal process between researcher and informants are of value to those who live and work with breast cancer and to other cancer patients who want and need to learn more about how others with breast cancer process challenges. Those individuals who agreed to do an interview for the research stated that they were eager to participate in order to have the opportunity to 1) tell their story in their own words; 2) to teach others with the diagnosis what it is like to have breast cancer, to potentially reduce the isolation such a diagnosis often generates; 3) to teach medical staff to pay attention to the needs of patients, and 4) to create some positive meaning of their breast cancer.

Limitations of the Study

The major limitation of this study is range of breast cancer diagnoses. There are different types of breast cancer and different stages of breast cancer indicating the degree of spread of breast cancer. Individuals who are in the later stages of the disease have more symptoms and need particular care and attention to their physical comfort during the interview, debriefing, and closure. After consideration, I decided to include individuals at all stages of the disease of breast cancer, from those newly diagnosed with minimal involvement, to individuals who are in remission, through to individuals who are terminally ill. The widest possible continuum of experience has the potential to generate the maximum amount of information and is most likely to illuminate universal themes. Another limitation is the researcher. The same questions from another researcher may

have evoked somewhat different answers. As well, a limitation was required in the demographics. A further area for research exploration would be in including women from other backgrounds.

Implications for Counsellors and Educators

This ethnographic work will offer counsellors and cancer patient educators specific and original data. The final report outlines a summary of tacit and explicit cultural themes that emerge from the expressions, words, images, and phrases used by those living with a diagnosis of breast cancer. At this time there is no consistent counselling guideline for those counselling breast cancer clients. Thus this research will provide information which is badly needed to guide counsellors. Issues that may be critically important to a client are often not raised, either by client or counsellor. This results from cultural taboos and the medicalization of the client's problems by medical oncologists, combined with the proximity of most breast cancer counselling venues to technical treatment environments. This study provides a framework to delineate counselling guidelines in the form of the themes and issues which emerge directly from the breast cancer informants' experiences and language.

Universal themes within this study, common threads running through the experiences of informants, indicate issues to be addressed in breast cancer counselling. This cross-sectional ethnography suggests new directions in breast cancer counselling in addition to Relaxation Training and Visualization Training. The results of this study also open the door to the possibility of dissipating some of the effect of taboos which surround discussion of breast cancer in our culture.

CHAPTER 4: THE ETHNOGRAPHIC TEXT

Living with a diagnosis of breast cancer is a complex and stressful experience in our culture. Each woman has learned to cope based on her own diverse cultural experiences and meanings which are not visible to the other, the outsider, the reader. In this chapter, biographical snapshots of each of the 13 informants are detailed in order to widen the perspective of the reader. This cross-sectional ethnography method is specifically selected to result in information to educate those in the health and helping professions working with women who have breast cancer, such as counsellors, psychologists, psychiatrists, physicians, and social workers. This mini/partial description of the culture (Spradley, 1979) from each of the 13 informants provides the readers with a basis for understanding the informants' personal context. Connections occur between and among our worlds and the worlds of the informants. These connections show up as recurring words, phrases, sentiments, metaphors and themes, and they emerge to form images as bits of cloth form a quilt, or as coloured tiles make a mosaic. All of the embedded and diverse themes of the informants' words contribute to an overall knowledge so that observers and outsiders can see and hear and know the cultural experiences of living with breast cancer. Cross-sectional ethnographies such as Spradley's (1970) *You Owe Yourself a Drunk: An Ethnography of Urban Nomads*, illustrate how clearly a subculture can be seen when depicted from the insider's point of view. My objective is to have the reader know the world of the culture of breast cancer from the insider's point of view.

. . . any good ethnography is always holistic; it is always contextual; it is always reflexive (Boyle, 1994, p. 159).

This chapter contains the introduction of the 13 women composing their lives within the context and culture of having a diagnosis of breast cancer. Chapter 5, the following chapter, provides the analysis and some discussion of 12 themes common to the majority of the women's lived experience. Each of the women is given a pseudonym unless otherwise stated.

The Women

YOLANDE

Portrait of Informant

Yolande was eager to be interviewed in order to share her experience with others. At the time of the interview, Yolande, born in 1931, described herself as a retired counsellor. She lives in a graciously decorated condominium in downtown Victoria, B.C. Petite and vivacious with naturally silvering hair done in a simple elegant hairstyle, she appears poised and confident. Her father was 7th generation Canadian and her mother of British background. Previous religious orientation is with the United Church of Canada, although she is not a currently practising member of the church. Yolande completed a B.A. in English Literature. Her three children, a son (38 years old), and two daughters (36 and 35 years old), were born by cesarean section. Stresses in her life include: 16 moves in her childhood; birthing three children by cesarean section in 3 years without support or help in her home; experiencing a depression in 1969; experiencing marital separation in

1972, and then experiencing a divorce in 1976. She said that raising three adolescents on her own was highly stressful.

Setting the Stage for the Ethnographic Interview

Yolande heard about the research from the Victoria Breast Cancer Foundation and called the University of Victoria to find out more about the research. We connected by telephone. After hearing about the purpose of the research, Yolande decided she would like to be part of the research. We set up an interview time. At her request, we made an appointment to meet at her home. Yolande invited me into her dining area for the interview. Setting up the tape recorder on the dining table in front of a stately Victorian sideboard graced with a gleaming silver tea set, I prepared for the session. We sat at the table with the recorder between us. Yolande stated she was somewhat nervous as she was uncertain what this interview would entail. She soon relaxed as she began to talk about her experiences in response to the first ethnographic question.

Diagnosis

Yolande was diagnosed with tubal carcinoma of the right breast in November, 1979, and had her breast removed by surgery in December, 1979. She has had no recurrence to this time. She has had two subsequent surgeries for breast reconstruction and says:

I have had breast reconstruction. In fact I have had two surgeries of breast reconstruction. The first one was not terribly successful, and then this second one has been quite successful. I am happy with it. And I mostly did it because it is so much easier for fitting clothes than with a prosthesis that keeps falling out or something like that.

She spoke about the many losses in her life, her depression and anxiety, and what the loss of her breast signified. She states:

Well I guess for me . . . I think I denied a lot . . . about the trauma of having a breast removed. But then I realized that it was difficult . . . Because I also had some depression and anxiety after the breast was removed, about a year and a half later. And I think that part of it was the denial of it. I was back to work in 3 or 4 weeks after I had my breast removed, and I think it was too soon. You know, 'what a hero I am.' But I think, as I told you on the phone the other day, that I think that you pay for it by internalizing a lot of the loss of it. Because again, it's loss. You see, and for me, I had other losses and it was just a build up of more losses too. But this time it has really affected me because I felt that there is a connection between my husband rejecting me and this . . .

I was concerned that if I got into another relationship with a man that I might be rejected, so I have never had a relationship with a man since I lost my breast. So I think that is very significant.

Despite her many losses, Yolande continues to live with enthusiasm, seeking a sense of “joie de vivre”. She is working at healing from her depression and anxiety and expects to do more travelling either on her own or in the company of her sister.

SHARON

Portrait of Informant

Sharon is Canadian, Caucasian, of ‘Heinz 57 mixed background’ (her words), and was born in 1936 in Montreal, Quebec. Her religious orientation is Roman Catholic, but she is not currently a practising member of a congregation. In Quebec, she graduated from CEGEP, the Quebec prerequisite for University. Her occupation is housewife; she was married in 1963, and she has two sons born in 1965 and 1968. Her spouse is 61. Her spouse’s education was a B.Sc. in Engineering, and he was employed with Imperial Oil

as a Chemical Engineer. After her husband took early retirement in 1990, they moved to Vancouver. Sharon said they really enjoyed their new life.

Setting the Stage for the Ethnographic Interview

Sharon heard my general invitation to participate in this ethnographic research project at the 1994 fall Breast Cancer Breakfast at the Vancouver Hotel. She later phoned me at the University of Victoria and left a message saying that she would be interested in participating in this research.

I thought, well, I'd love to tell my story to someone just so it would help somebody else.

We made an appointment to meet in her Vancouver West End apartment for an interview. The apartment has a large window overlooking Stanley Park. This view of the park so filled the eye that the rest of the apartment appeared to be a frame for just this vista. I was invited to set up my tape recorder on a dining room table and the interview proceeded. Although Sharon was somewhat nervous to begin with, she had a very pragmatic way of dealing with the facts of the experience of having breast cancer.

Probably the most stressful thing that I was hit with, and for my husband, too. He was very upset by the diagnosis, every time he looked at me he burst into tears, because he thought he was going to lose me. And he may yet, who knows? But after all, life is terminal.

She believes she has had a very good life, and stated the breast cancer experience was by far the most stressful time of her life. Her husband, though retired, continues to work with their two sons on renovating an old house in Burnaby. His retirement was very stressful for both of them as he was given a golden handshake at 57 years of age. His work had

been his whole world, then suddenly he had nothing to do. The stress of his remaining at home all day was difficult for them both.

Diagnosis

After their move to Vancouver, Sharon thought they should find a new doctor and get a medical examination, but she kept procrastinating. When she did find a doctor and went for a check-up, the doctor requested that she have a routine mammogram. She states:

. . . this lump showed up on the mammogram and then they sent me off for an ultrasound and then they decided to do a needle biopsy. And you know, it's really funny, they sort of rush you along and you're like a piece of meat. You're never treated like a human being, even though they're caring and they aren't aware they're doing this. I did say at one point, "You're not going to operate today are you?" "Because", I said, "My husband's expecting me home for dinner." But that's how little time they give you, because they just rush you along.

The mammogram showed an 8 mm suspicious area. The date of her original diagnosis was May 14, 1993. She stated she was post-menopausal, and listed her menopause as beginning in 1990. Her surgeon recommended mastectomy, with the surgery date of June 21, 1993, five weeks after her diagnosis. Her sense of humour as a way of coping is illustrated as follows:

I went in for the operation, and I knew they were doing a change of Residents the week of my operation, and I was sort of in fear and dread. You hear of mistakes in operations where they remove the wrong things. So I decided a sense of humour would help things a little bit in the operating room. So I had an arrow, pointing down to the left breast saying, "This is the one," and then I had a cross on the other breast saying, "Do not touch."

Her drug therapy is a regimen of Tamoxifan only.

Sharon states:

I think they said I had breast cancer in the milk duct, and it had spread to 10 lymph nodes out of 20. The cancer itself was very small, it was 8 mm, and the surgeon had not expected it to be cancer because it was symmetrical and he said, "Cancer's invasive." And he was really very surprised to find that it was cancer.

Sharon is quite philosophical about her future. She reads a lot, though she has not always found the books she reads of help. Some of the assumptions that some authors of cancer books hold, such as Siegal's (1989) statement that 'everyone wants to live to be 100 years old', she found offensive. She believes in living life to the fullest in the present and hopes her story may be of help to other women.

ELAINE ZYRI

Portrait of Informant

Forty-eight-year-old Elaine Zyri stated she would like to take part in the research and would like her name used. She is a slight woman, with regular features, and thick blonde curly hair. At the time of the interview she appeared to be calm, perhaps even a bit tired. Her eyes crinkled with relaxed good humour as she studied me with open curiosity. Later in the interview she tells me that she is bald and that she is wearing a wig. I admit that I cannot tell the difference. During the beginning of the interview when we are reviewing the parameters of the research project, she slowly sips Perrier water. She states:

I've tried it all. I've tried at least 25 different brands of water, pop, all kinds of concoctions and that's the best . . . It's got the fuzzies, that helps take away that metallic taste from your mouth, from all the meds. And it's very refreshing. You have to drink lots of water when you've had chemotherapy, so I drink tons of that stuff.

Her religious orientation is non-denominational; however she states that she has strong faith. Elaine is currently taking a leave from working on her Master's degree in Nursing at the University of British Columbia; she states that it is on the back burner at the moment because of her health. Of Eastern European origins, Elaine lives on Vancouver Island in a small tourist community on the coast. She was divorced in May of 1982 and has no children. For the past 5 years she has been living with her 43-year old-partner who is in the marine tooling business. She spends time at both the hospital in Victoria and at the Vancouver Cancer clinic with her ongoing breast cancer treatments.

Setting the Stage for the Ethnographic Interview

During my clinical internship at the B.C. Victoria Cancer Clinic, I advised the Clinic staff of my research and they invited breast cancer patients with whom they worked to take part in this research. Elaine heard about my research from one of the counsellors at the Cancer Clinic in Victoria and indicated she would be interested in taking part in this research study. I called long distance to her home several times before connecting with her. She had had an experience of being battered by her partner, so had spent some time in a Safe House. After that she discovered she had a recurrence of cancer and had been staying with her mother. After talking on the telephone with me, Elaine decided she would participate in order to inform others about her experience. In deference to Elaine's request that she be interviewed at the Cancer Clinic, we set up a meeting in one of the comfortably furnished counselling rooms at the Victoria hospital clinic. Seated in a wingback easy chair in the quiet counselling room, Elaine indicated she was ready to

begin telling her story about her experience of breast cancer. I sat opposite her with the tape recorder on a small table adjacent to her recliner chair.

Diagnosis

The original date of Elaine's breast cancer diagnosis was January, 1991. Shortly thereafter, she had a full mastectomy. The lymph node surgery indicated that she had 5 to 7 nodes positive. Since then she has had three recurrences. Her recurrence dates are July, 1992, December, 1993, and July, 1994. Her first metastasis was in her lung, the second and third ones were in her right hip and spine. Presently it is back in her lung, again. In first mentioning her treatments, she stated:

I've had CMF (cyclophosphamide, methotrexate, and 5-fluorouacil) originally, and then for my next two metastases I had radiotherapy. And now for this recurrence, I'm on Taxol every three weeks, and I've had radiotherapy to my breast bone and a commensurate therapy to my rib area . . . I am not a well person. I know that my Taxol only controls my cancer. It's not going to cure my cancer.

Stress plays an important part in the etiology of her illness, according to Elaine. She was working as a nurse in the Victoria Cancer Clinic 10 years ago when she received a call informing her that her brother-in-law had been killed in a plane crash. When she called her husband at work to relay the information and make plans about travelling to the funeral, she heard her husband say that he was moving in with his girlfriend and would not be coming with her. Elaine stated that she believes the stress of a traumatic separation and divorce, as well as an extremely abusive childhood and adolescence, negatively affected her immune system's ability to function. After her marriage broke up she states:

My world fell apart . . . and then I got into a depression, and then one thing led to another, and finally I guess I had a nervous breakdown and went off in long term disability in 1984.

Elaine also stated that she always had a certain sadness about her and she believes it was rage turned inward from the years of abuse. She states:

I've always said that, that I've always had a certain sadness about me. I thought my cancer happened because it was rage turned inward. I've always been very upfront about that. The thing is that it's finding the skills in order to get rid of that rage and turn it into constructive process. And I really found that when I started working on my Master's degree. I did a lot of travelling and teaching primary health care to immigrant women and their families. I did a National Film Board film this summer on that, and it sort of took away some of the rage. Because I could see where those women, or their child, would be in the same situation that I was in, I sort of felt like I helped a little bit.

Currently Elaine is planning on leaving the physically abusive relationship she is in. However, her health takes centre stage at the moment. She works when she can and lives life fully one day at a time.

CAROL

Portrait of Informant

Carol is a petite, 48-year-old woman of Scottish origin. Her accent is slight, but becomes more noticeable when she becomes agitated. With strong conviction in her faith, she is a present member of a Presbyterian congregation. She has done some post-graduate work at the university level and is a manager of an occupational health program. She has never been married and has no children. Although Carol is physically not very tall and of very slight build (she has to be reminded to eat at times, she states), she exudes energy and passion as she talks. Living alone in Vancouver, she has a coterie of friends and

church members who support her. Her parents came up from California to be with her for some of the difficult times after her breast cancer diagnosis.

Setting the Stage for the Ethnographic Interview

Carol responded to my research appeal at the October, 1994 Breast Cancer Breakfast in Vancouver. After a preliminary telephone interview, we set up an appointment in her office in downtown Vancouver. Our research taping session took place in a quiet, spacious, middle-management government office decorated with comfortable, functional furniture. I was somewhat early and Carol was a bit late, so I had ample time to relax, set up my equipment and prepare for the interview. Carol's bright smile greeted me as she welcomed me to her office. After some general discussion, we began the ethnographic interview.

Diagnosis

Carol discovered the lump April 11, 1992. However, she did not have a diagnosis until the 15th of October, 1992. Her words follow:

I was just sitting. I was watching TV and I was in my nightclothes, and I thought, gee, it's itchy and I scratched, and I thought, oh, it was actually just there. I do breast self-exam, but anyway, I promptly did a breast self-exam. And then very quickly, (my background is nursing), I pulled down some textbooks and then went to Our Bodies, Ourselves. I was frantically flipping through, and I thought, okay, okay, now you know, where are you in your cycle and so on . . . So I said to myself, I will wait because I was sort of mid-cycle, I'll wait and see if it disappears after I menstruate, and if it doesn't, . . . Well, I waited for about ten days and it was constantly on my mind.

Eventually I went to my own GP and she referred me quite quickly to a surgeon who deals with breast cancer patients. And I went for the mammogram . . . and nothing showed up. He said, "We think it's cystic but go see the surgeon." I went to see the surgeon a couple of days after the mammogram, and he said, "I'm pretty sure it's a cyst." He put in a needle, drew off some fluids, and said, "It's

cystic, so, great.” He said “We’ll see you in 3 months.” (Client emphasis). And I went back in 3 months. And I wasn’t sure, inside myself. But part of me said, “Great.”

I can remember getting on the bus and it was a beautiful day and you know that clarity of vision you have when suddenly your life is back in your control, I had that. But by the time I got back home, I thought, “I don’t think so.”

Anyway, I waited the three months and went back for another mammogram and the radiologist . . . She looked at the mammogram and she said: “You know, it still looks as though it’s cystic, but I’m not sure. We’re going to do an ultrasound.” Which she did. She said: “I’m going to be compulsive.”

And I said: “Please be compulsive, be my guest. This I can relate to, be compulsive.” So she did the ultrasound. And she said: “I’m going to do a biopsy—I’m really being compulsive.” And I said: “That’s fine.” She said: “We’ve missed the runner, so would you take it over to St. Paul’s?” And I said: “Absolutely.”

I was due to see the surgeon that afternoon, and so I did that. And by the time I got into the surgeon’s office, I said: “Did you get the results from the biopsy, the needle aspiration?” And he said: “No. What needle aspiration?” So I said: “I did one this morning. Please call Dr. P.” So they said: “Okay, we’ll call around.” So I went into the surgeon’s office, and I heard him outside the door. And he came in and he said: “We’ve got suspicious cells.” And I said: “Okay.” I wasn’t surprised. So I said: “What do we do now?” And he said: “What we’d like to do is book you in Outpatients, and do a biopsy and do a frozen section and then we’d take it from there.” Fine.

So that was booked for the following Wednesday, and I duly turned up at Vancouver General Hospital. What I didn’t realize was, I was so badly bruised from the needle aspiration that when I went in for the biopsy, he couldn’t find where he was supposed to go in . . . I liked the surgeon, but there was something about him I wasn’t quite happy about, and this was the final straw. So I said to him: “Where are the ultrasound films or results?” And he said: “I don’t have them.” And I said: “Then why don’t you have them?” (pause)

He said: “I’m sorry, but I couldn’t go in there anyway, with all that bruising.” And so I said: “What are we going to do?” He said: “I’ll book you for a week from today and we’ll do it by then. Before you come in, I want you to go back to Dr. P. and have a wire inserted.”

So I did that. And I was mad, ooh, boy I was mad. I could have punched him. I was so angry with him. I went back a week later and had the wire inserted, and he

did the biopsy, and he did a frozen section, and he came out to the waiting room and he stated: "It is okay, everything is fine, no problem. Great."

So I go home and I sleep it off. And that was a Wednesday. I was to call in Thursday just for confirmation, which I did. And his nurse said the pathologist's results weren't in but she'd have Dr. C. call me. And I thought, "Yeah, I bet he will." You know, when you've been in the health business, you know the minute they tell you 'we'll have the doctor call you,' it's gone from, it's negative to, it's something.

So he duly called and to give him his due, he said to me: "Ms. A., my apologies, you were right and I'm glad you persevered." And that's how he told me. So right there I shifted in how I felt about him, because this man can admit his mistakes. And you know, surgeons are not always renowned for small egos. So I went in the next day with a friend to his office, to discuss, "Okay, where do we go from here?" And he told me that his recommendations were surgery, including the lymph nodes, of course. He recommended radiotherapy, and probably chemo.

Carol received a diagnosis of in situ carcinoma with some invasive cells. No recurrences were found as of November, 1994. She had a quadrectomy with lymph node removal, a bone scan and radiation. She finds that she is able to find perspective in her life now. Things that used to upset her now do not. She states that, as a result of having this cancer, she has the ability to step back and say, *"Yes, this is pretty awful. But, in the scheme of things, does it matter?"*

DONNA

Portrait of Informant

Donna walks to and from work daily to Vancouver General Hospital where she is employed as a secretary in the Department of Anesthesia. At the time of this interview she was 59 years old. Donna is a single, tall woman with a medium frame who emigrated to Canada from London, England in 1957. Her religious background is Anglican and her

formal education includes college and some university. From 1981 to 1989 she looked after her elderly father who was in failing health and incontinent.

Setting the Stage for the Ethnographic Interview

Donna contacted me at the University of Victoria after having picked up one of my handouts circulated at Vancouver Cancer Clinic and the Breast Cancer Breakfast in Vancouver, October 1994. We connected by telephone at the university and set up an appointment time. She invited me to do the ethnographic interview at her apartment in central Vancouver. I arrived early for our appointment and waited outside an attractive, small, white apartment building until Donna arrived from work. In a faint but clear British accent, she discussed the hazards of walking along main streets in large cities as we made our way to her apartment. We entered together. Donna made sure I was comfortably seated, then spent a few minutes organizing herself after a day at work. Arranging the chairs so we could sit comfortably adjacent to one another with the tape recorder between us, Donna then sat down. For a short time we conversed about general topics, then Donna suggested she was ready to begin the ethnographic interview.

Diagnosis

Although Donna says she is not very good at doing breast self-examination, the evening before a medical appointment she examined herself and discovered a lump on her right breast. She saw her doctor the next day, May 3, 1994, had a mammogram and an ultrasound on the 10th of May, and a biopsy on June 15, 1994. She was given her diagnosis on June 28, 1994--that she had breast cancer but that it was a contained, rounded, lump. She agreed to have surgery, a lumpectomy, although she wondered

whether she should have a mastectomy since her two friends had had them. Her doctor stated dryly that “if she [the doctor] took Donna’s breast off, she wouldn’t be able to sew it back on again.” Her lumpectomy was on July 12, 1994. She was in hospital 3 days and was sent home with a tube for drainage as it was still draining a bit. She states:

I went in on the following Wednesday, and she (the doctor) took out the drainage. But it was a bit too soon, because a week later I had a terrible eruption of the liquid coming right out. Fortunately, I was in the bathroom. It just poured out, and I let it pour, and then I came out and I put a bandage on. But that got all soaked. I was talking to a friend and I said, “Oh, I must go get a tea towel.” So I put that under, and that got all soaked, and then I put another one on during the night and that got soaked. So the next day I called her office and they said to come in right away . . . (The doctor) said: “I wanted you to come to Emergency . . . so I can open it up a bit and get some more of that liquid out.” So he did open it up . . . and of course, it had gone inverted a little bit . . . The doctor (a different doctor) wanted to open me up again and I said, “No, it doesn’t bother me. I don’t want to be opened up anymore.” She likes straight lines, she said. So anyway, it healed up and the antibiotics took effect and then I had to wait for the radiation to start.

After a long wait of 10 weeks until September 27, 1994, Donna began her radiation. She had to wait both because of the infection and the long radiology waiting list. She had side effects that mostly affected her stomach as well as a great deal of “reddening of the bust.”

With the booster shot they mark with a little square just around the lump. That got very red and I broke out in a couple of little blisters for which they gave me hydrocortisone . . . Two weeks later, it is back to normal. It is just slightly red at the moment.

Donna is really clear that the breast cancer diagnosis and treatment are much less distressful than her previous colostomy. To support her, she has two friends who also were diagnosed with breast cancer and who were there for her during the surgery and treatment phases. Her physician stated clearly that the lump was contained and there was

no lymph node involvement, so she has confidence that her treatments are successful. She has returned to work and continues to read up on all the information available on breast cancer.

LAURA

Portrait of Informant

Laura was born in St. Vincent in the Caribbean 50 years ago. Her only child, a daughter, is 28 years old; she has a two-year-old grandson and an adult nephew who, she says, is particularly dear to her. Laura has a soft lilting cadence in her speech reminiscent of her birthplace in the Caribbean. Her appearance is that of a business woman. She is of average height, and is comfortably rounded. Holding her head up with dignity, she walks slowly but steadily and sits down opposite the coffee table in the hospital chaplaincy interview room. Deep sadness is etched on the planes of her face. As she begins telling a little of her life in the opening part of the interview, she pauses often between phrases and sentences. She continues to speak slowly, haltingly, coughing frequently, throughout the interview.

Until this illness, Laura has been working as a professional housekeeper. She wants to return to work immediately, as she states that she feels better when she is busy. However, her doctor has suggested that she be off work for at least 6 months. Her family and friends have been extremely supportive of her 'operation.' They do not know the specifics of the surgery. She has not told them that she has had a breast removed and indicates she is intensely shy about letting anyone know. Her fear of the word 'cancer' is clear from her shiver as she tries to find another way to say, to her, the unsayable. Her

sister died of lymphoma several years ago on 27 June, 1993. Thus she has legitimate and concrete grounds for her dread of cancer. Until the present, she has had no serious ill health issues. Her religious faith is very strong and she is a devout practising Anglican.

Setting the Stage for the Ethnographic Interview

Laura heard about this research study by word of mouth, from a friend of a friend in Toronto. We talked on the telephone and agreed to do the interview for the research study at one of the meeting rooms at Princess Margaret Cancer Hospital in downtown Toronto, where Laura is currently receiving both chemotherapy and radiation. She has been scheduled for 25 sessions of the radiation and, at the time of this interview, has nearly finished the program. The chemotherapy continues for 6 more months. The interview room was small, but pleasantly comfortable with drapes, easy chairs, and a sofa, all colour coordinated with a pastel green floral motif. On the coffee table in front of the sofa, a small bouquet of fresh flowers filled the room with a subtle spring flower scent.

After discussing the research project, we began the ethnographic interview. She declared she was interested to share her experiences so that the knowledge she gained might help others. She believes that her total ignorance about cancer, and breast cancer specifically, had handicapped her ability to understand and accept what was happening to her. She then spoke of life generally as if preparing herself mentally to talk about what was, for her, an unspeakable subject. When a natural lull appeared in her conversation, I asked Laura if she felt comfortable about beginning the interview. As she responded

positively, I set up the tape recorder on the coffee table and began the ethnographic interview.

Diagnosis

Laura spoke about how this experience began for her:

One day I was taking a shower and I noticed something. It was a (pause) . . . hard thing. And when I was speaking to my sister and told her about discovering this lump in my breast, she told me she thought I must go and check it out.

So I went to my family doctor and told him. I was afraid he was going to tell me it was cancer. He told me since it didn't hurt, it was cancer.

. . . So he made an appointment for me to see a specialist and to take a mammogram. So I went to see the specialist and he said: "We have to work on it right away." He had to take a test to find out if it was cancer. So he took the test and it didn't come back as cancerous. Then they did a small operation.

They did a biopsy first to find out whether it was cancer or not. But it didn't show up as cancer.

So he told me I was going for the operation and if it was cancer, he would take off the breast as far as he had to . . . I said, oh my . . . I remember that . . . And when I woke up after the operation, and I saw . . . ooh, no breast . . . Then I was crying. I asked for my nephew. So then they took me upstairs. And my nephew was with me. My nephew went to ask someone to come and speak to me. I think she is . . . a Social Worker. She asked me if I wanted to see a minister or someone who had gone through the same thing. And I was so (long pause) . . . that I said: "Speak to my nephew." My nephew said to send someone who had gone through the same thing. Anne came to the hospital. She was so supportive. She was by my side. I will never forget that day. And then the social worker came the next day and brought the lady from the Cancer Society. She came and brought something for my breast. A form like this . . . (she leans forward and opens the top of her dress to show me the resulting shapelessness of what remains of her breast against the pink prosthesis which contrasts sharply with her soft brown skin).

Laura does not want anyone to know that she has had a breast removed. For the present she has cancelled her trips back to her island home as she feels she cannot swim or go on the beach with her family with only one breast. She states with wry humour:

When I visited my family doctor, he said he was going to check me every year for diabetes. I was not looking for cancer, I was looking for diabetes.

Grace and humour are both apparent in her demeanor as we do debriefing and closure of the interview.

ROSE

Portrait of Informant

Rose is a survivor of a Holocaust concentration camp in Poland as well as a survivor of a diagnosis of breast cancer. At the time of the interview she was 75 years old and states her occupation as semi-retired housewife. Her late husband died of heart disease last year; she has one son, age 46, who works in computers. Rose states she comes from a 'family of women.' She had four aunts and is the middle sister of five sisters. There is no breast cancer in her family history. Her strong faith helped her survive the stresses of World War II as illustrated in her current belief statement that:

God is part of every human being. God is not external--we must look for God in ourselves.

Rose is a tiny woman, under five feet high, with a large bosom. She believes that medical error and undue haste are responsible for her losing her breast. As her breast was a large part of her body, it has affected her balance, her back, in fact, all physical activity. Her visits to the doctor subsequent to her surgery indicated that a lumpectomy would have been just as effective. She wants to tell about her experiences so that they may help other women:

The first thing I want to say to women is: "Don't lose your head." Because I lost it. I didn't have anyone to talk to. I still had my breast--I should have asked for

another biopsy. I was in such shock that I didn't think straight. I will say this again and again: "Women should not panic. They should take some time, and think, and ask questions." At that time, 15 years ago, there was no one.

Setting the Stage for the Ethnographic Interview

Word of mouth through the medical profession in Toronto resulted in Rose's responding to this study. I was given her name and number by a colleague in the medical profession. Rose was very interested in research that encourages women to contribute their experiences. She chose to have me come to her home. We set an appointment. She lives in a large, high-rise condominium complex across the way from one of her sister's homes. The sisters all live in the same area of North Toronto. Rose showed me in to her light-filled home, and we debated whether to go into the large elegant dining room or the sun-yellow bright small kitchen. In the end, she chose the kitchen as being more comfortable.

Rose is a petite, lively, spirited person who appeared very cheerful and very healthy. She admits that she has changed her lifestyle somewhat after the experience of the surgery, particularly in diet and exercise. Her nephew is a chiropractor and has studied naturopathic medicine. He worked with her on the subject of the value of a healthy diet.

At the beginning of the interview, we discussed confidentiality and reviewed the letter of consent. Rose asked several questions about ethnography and research and we discussed the cultural aspects of cancer for a bit. In response to an ethnographic question, with a frequent shake of her head for emphasis, and with a strong, clear voice, Rose related her experiences after her diagnosis.

Diagnosis

After a routine mammogram, Rose was diagnosed with ‘invasive cancer’ 15 years ago. Her surgeon prescribed a radical mastectomy immediately after the diagnosis. Her cousin is a surgeon, and when she told him of her diagnosis, he said, “*Take off the breast. Don't think twice.*” Later, however, it was found that she had been misdiagnosed and that a lumpectomy would have been much more appropriate. Rose is passionate in her request to other women who are diagnosed with breast cancer:

First of all, know your body. Then don't lose your head. Sit and meditate. Think: What do I have to do? How can I help myself? . . . Use your head. And talk to people, get different opinions while you still have your breasts. Every doctor seems to do things differently. Again and again, before you do what the doctor tells you, check and recheck. Check three times before an operation, any operation.

Rose leads a full and busy life. Her social schedule is very busy both in Toronto in summer and Florida in the winter. She is an avid consumer of medical books and health programs.

VERA

Portrait of Informant

At 84 years, bent over nearly horizontally from the waist up from her spinal bone cancer and concomitant radiation, Vera is a feisty seven times survivor of cancer. She had breast cancer twice (once in 1958 and then in 1993), bone cancer four times (1959 to 1971), and bowel cancer (1991), all but two of which currently appear to be in remission. She has been a housewife for most of her years, and occasionally worked at the local public library part-time.

Vera was born in Alaska and was raised in New Brunswick. Her mother died when she was 12 and her father remarried twice. When Vera married, she moved to Toronto where she has remained. She has two children, both overseas. Her son is with Canadian International Development Agency (CIDA) in Africa and her daughter is with the Canadian High Commission in Zimbabwe. Her husband, a lawyer, died in 1969 of a heart attack. Vera has a strong religious faith and is still an active member in the United Church. She states that attending to her faith has “. . . *an actual physical affect on me. Counteracting the absolute terror that you live with.*”

Setting the Stage for the Ethnographic Interview

By word of mouth, Vera heard of this research study. When I heard she was interested, I called and we discussed the research on the telephone. At her request, I made an appointment to meet with her at her home in Etobicoke, West Toronto. Her bungalow is surrounded by shrubbery in the front and is bordered at the back by St. George's Golf Course. We sat in the fully screened sunroom at the back of the house facing the trees, hedges and greenery of the golf course. A restless vociferous crow in one of the large trees out back cawed raucously as if we were disturbing its nest-building process with the murmuring of our conversation. Vera reclined on a cushioned chaise. I sat adjacent to her and set the tape recorder on the coffee table between us.

Diagnosis

In 1958, at 47 years old, Vera was treated with surgery 2 days after discovery of the wrinkling of skin on her breast. She states she had a mastectomy so complete that the . . . *scar goes from my collarbone practically down to my hip. I was fine. I didn't go on*

any treatment whatsoever. A year later she was diagnosed with bone cancer and was treated with radiation and chemotherapy. One of her previous assumptions was that early diagnosis is helpful. She states:

One of the things I'd found out early was that early diagnosis is so helpful. But not maybe as much as people think it is. Because at the same time as I had my operation, the next door neighbour of my cousin, practically my family, she had hers. She had known she had the lump from the beginning of July (this was September), but her son and family were coming home from Vancouver in the summer. She wasn't going to spoil it for them, so she just waited. Well, I didn't wait at all. Also, with me, the lymph nodes were not involved. And hers were. But she never had a recurrence, in all those years. And I did. So many of the things that you think of as signposts don't always . . . The one thing that comes out of any cancer study is--it is an individual disease for every person who has it. There is no such thing as an overall cancer. It is cancer for you.

Vera was on radiation to the ovaries and was then given a form of steroid/testosterone and was on it for over 25 years. During that time doctors discovered bone cancer in four places in her body--each hip, the spine, and the top of her neck in the cervical area. She states: *I would go along for a couple of years and then it would start somewhere else.*

When her daughter had a medical, they wanted her background:

And she told them, "My mother has bone cancer." They said, "How long has she had it?" She said, "Ten years." And they said, "You must be making a mistake." (Vera's laughter.)

Vera lives fully, one day at a time. She has always ignored limits and continued to enjoy life to the maximum. The following quotation comes from an author, a friend of Vera's, an African safari leader, who included a story Vera wrote in his book on South Africa:

When I copied an elephant story by Vera M., I promised . . . I would explain . . . she is . . . something of a miracle. She had a mastectomy in 1958. The cancer spread and she was told to live a day at a time.

Some might have slowed down their travel and adventures after such a diagnosis. Not Vera. She continues to live one day at a time, enjoying every minute possible. Her deep connection to Nature, her spiritual belief and her strong will to make the best of whatever comes serve her well. She states:

And my joy has come mainly from the fact that since I have been a very small child I have been so responsive to the wilderness and to nature and to animals. This has been probably the most important influence in my life. I was saying something the other day --Do you know something about myself that I have just discovered -- that the things I really remember passionately always involved animals of some kind. You see, I cry when I hear Loons, when I even think about Loons.

And my safari experiences. You feel as if you go back to the beginning of time. And you are there in the world. I'm not talking about the kind of safari where you have unlimited buses running around and you see one poor little animal with ten buses around it. I'm talking about the kind I did where you have a guide and there was nobody else around but the few people you were with. And the people you were with were not there because of an advertisement. It was word of mouth and you formed your own group. And you never took more than five people. Once C. and I had a week entirely on our own. We could never have afforded it but for ... We wanted to go badly at Christmas, the first year she was in South Africa. We couldn't because he was booked solid. He suggested we go a week earlier. So we had Robert and the whole staff to ourselves for one whole week.

Because at that time of the year there were very few people down in the Mara -- you know, the upper level of the Serengeti, although it is in another country... Yes, spiritual. I can remember one morning that I have never forgotten. You had a tent of your own. Couples had double tents and single people had single tents. And you had what's called a loo tent. A loo is Swahili for toilet. And you'd get up in the early morning and go to the loo. One morning, I went up. We had a camping area that was surrounded by a ring of trees. And beyond that, just grazing, meadow area.

When I went up to the loo -- I'd almost got there -- I saw a waterbuck. Just standing there, at the edge. Not too far from me. Perfectly still. Looking me. And I stood perfectly still. And we stood there, looking at each, for... I don't know... maybe five minutes. But maybe it wasn't that long. And then he, very slowly, turned around and walked, very slowly, away. Quite aware that I was... and

certainly I was sure he was no menace to me. He was one ... large animal. Beautiful. You felt, at that time of the morning, before there was any noise from the kitchen area where the men get breakfast ready, there was nobody up but you. The world was new and you had found it, yourself.

And I'm convinced that this is another one of the things that I was so fortunate in having. I don't understand the physical part of the whole thing, what happens to you spiritually, or intellectually, but it does change your body..

As the survivor of seven cancers, two of which are still active, Vera still finds the energy and time to keep going and find joy in every day.

ANNE MARIE

Portrait of Informant

Anne Marie is a 56-year-old Registered Dietitian working in a large urban hospital. She married in 1963 and divorced in 1976; she has two daughters, age 28 and 29. She describes herself as Caucasian with a British background and states she is of the Anglican faith.

Anne Marie believes the multiple concomitant stresses in the years preceding her diagnosis have a lot to do with her illness. She had an abortion and a stressful marriage.

In her words:

My marriage was very stressful. My husband in 1972, was very, very ill; he became very ill with cancer. And we had a struggle for a few years, with a young family and 2 years of intense treatment for him, because it was a major tumour of the back of the spine which spread through the lymph nodes to the lungs. I think it was constant radiation; I think the radiation was killing him as much as the cancer was.

Anyway it was very stressful, because at that time there was no support. There was really very little for what's going on in the cancer world. There was the old Cancer Clinic, around there; there wasn't even a dietitian that worked in the wards or anything. It was mainly a lot of your own family care. And many people were not there for you, probably because they were so afraid. Of course, they

thought: "This guy's not going to make it. He's going to die." Well, he survived, after many, many agonizing recoveries of everything. Because it was total body radiation, everything just fell apart and grew up again.

In those days, I don't think the radiation was refined or anything. So I had that stress. I was very aware of cancers and what was going on with cancers. And he survived and he's alive today. He's an airline pilot. So I classify that as a stress. And my marriage was very stressful. There was a bit of abuse and all that sort of thing. And I think we probably had excess alcohol, all those things

Anne Marie had experienced abortion, separation and divorce, and was caring for her senile father and for her ex-husband who had cancer recurrences:

. . . looking after the kiddies, plus the ex-husband then re-got cancer, if you can imagine. So it was "Can you come and help me?" "Of course. Of course." As well as my own problems here. He actually had some more surgery, and this time it was in the testicles. They removed a testicle. And then they figured the next thing they had to do was strip the lymph nodes. So he had major surgery, and then his pancreas failed. So, in the midst of all my problems, I was running down with the kids to the hospital to visit him.

Although Anne Marie agrees that this was a stressful time, she minimizes her experiences by saying: *It's not bad compared to what I see at the hospital, people who go through stress.*

Setting the Stage for the Ethnographic Interview

Anne Marie called me at the University of Victoria to find out more about the research project posted at the hospital. She decided she would like to participate. After some discussion, she chose to have the interview take place in her home in Vancouver. I arrived after one of Vancouver's rare snowfalls, slipping and sliding along the icy street. Her house and its adjacent trees and shrubs were decorated with melting snow and ice crystals. Anne Marie invited me in and led me to a bright kitchen. The sliding glass doors looked out over a sun deck sparkling with a fantasy of dripping icicles and snowfrost

designs. I set up the tape recorder in the centre of a modern glass breakfast table while she said good-bye to her friend who was just leaving. She rejoined me cheerfully and sat at the table opposite. After completing some introductory exchanges, Anne Marie responded to the first ethnographic question and began describing her life experience with breast cancer.

Diagnosis

Anne Marie begins her story:

I would start with saying my breasts have always been lumpy, and a problem. So I started having mammograms, probably, beginning age 40. And that was the old days when the old mammograms were something. It's the funniest thing. There's a table that you're lying on, and you don't have a choice. You have to lie down. There's no standing up at all. You're lying down while they do it, and they have to turn you over and the whole ball of wax. It seems like there was a cone coming down and they had a big balloon in it. Then this would come down and compress you, so that you lay down for the whole process. I started that way back when, so that's 15 years ago.

That's my first experience with it all. And every year it would be, "Oh, we'd better go do it." So it would be that I was sent by my family doctor, and I was always concerned, to these various places. He didn't want one reading only from one place so I went to various mammogram x-ray places to have this done. Finally, it ended in Fairmont, with Drs. W. and G., two ladies. Then when the screening mammography program came about, I went there. So it was then they actually picked up the actual cancer on this mammogram. And that mammogram is the one that's being used for teaching at UBC (University of British Columbia).

Anne Marie volunteered to take part in a hospital research study of women with breast cancer using Tamoxifan. The date of her original diagnosis was August, 1993.

She describes her diagnosis and treatment:

It is in situ ductal carcinoma, and multi-sited lobular neoplasia . . . That was what they called the wide local bulk removal and radiation. The other reason they call that wide local bulk removal, because with the ductal in situ, there is no actual

finding of a lump. So they do not call it a lumpectomy, they call it, "taking out the bulk," and that's when they find the other site. The neoplasia are funny things.

One of Anne Marie's many coping strategies is to put her breast cancer experience in perspective:

... it's like I look at my cancer, and I think, "Oh God, that's so mild." I went through all that with my husband. It was major. Mine is just mini, mini of the big gamut of what it could be. Because I look at others and think, "My gosh, they're going through chemo and their hair's all falling out, and they're sick." Mine's just a little weeny bit in the gamut of what could be.

Anne Marie believes that the breast cancer is just one more learning experience. She finds that it has helped in her job of counselling others.

MARGARET

Portrait of Informant

Margaret was born in 1931 in Montreal, together with her identical twin sister, of Slavic heritage, the second youngest siblings in a family of six children. Her father left the household the year after they, the second set of twins, were born, so the girls never knew what it was like to grow up with a father. Although Margaret believes in prayer, she does not attend church. She has spent all her life in Quebec, aside from jet-setting around the world with her husband (married in 1952) and two adult children (a son, age 40, and a daughter, age 35) who are in the high fashion importing business. Margaret is a tall, slim blonde who carries herself with grace and dignity. Her identical twin sister has never had cancer or any serious illness. Margaret and her husband presently live with comfort and style in a French designed condominium in an exclusive area of Montreal, and they also spend time travelling and entertaining at their country property in upstate New York.

They winter in their Florida residence. Despite this recent relative luxury, Margaret survived a harsh childhood and many years of gruelling hard work assisting her husband in starting and expanding his business. Over a period of time, Margaret has been receptionist, secretary, bookkeeper, and part-time sales person. She has recently retired, and is a picture of tanned glowing good health as shown by her physical fitness combined with her relaxed and confident demeanor.

Setting the Stage for the Ethnographic Interview

While she was visiting in Toronto, word of mouth reached Margaret about this research and she decided to participate. Throughout her surgery and treatment time, she actively sought out materials to read in order to learn more about how she could help herself with this disease. There was very little available for the lay person to read in 1976. She was interested to be part of a study which would help inform others. Just before beginning the interview, I adjusted the sound on the small recorder to accommodate her clear, strong voice.

I am glad to be doing it. I think that if I had this story to read while I was going through it, it could have helped me . . . Like everything else, you handle it alone. But if you have somebody's true story, like my story or anybody else's, it helps ...

Diagnosis

Margaret began her story in response to my opening ethnographic question. In 1961, she states, a cyst was removed from her right breast. No health problems occurred for 15 years. A call from the doctor's office after a routine mammography in mid September, 1976, alerted her to the possibility of another cyst or lump. It was a lump and a biopsy was recommended. Within a month she was in the hospital. Because the cancer

was extensive, both radiation and chemotherapy were prescribed after surgery. The radiation lasted for 6 weeks, the chemotherapy for 3 years. One of the side effects was that Margaret experienced extreme swelling (lymph edema) of her arm. Since the muscles were cut across the breast, Margaret had difficulty in lifting and moving her arm. After years of self-help exercises and some physiotherapy, Margaret now plays a good game of tennis. Immediately following surgery, Margaret began intensive self-teaching, seeking out information from many sources to help herself. Her experiences with the medical profession were mediocre at best and she decided that if no one was going to help her, she had better help herself.

Time passed slowly. I read whatever I could on the subject, the two, then five year stages. Without realizing, I turned inwards, towards myself -- analysing my strengths, weaknesses, hopes and fears. I was certain of one thing -- no one could help me. I needed me first. My attitude began changing. Physically I worked very hard at anything I did. I learned that I was a determined person. I also learned who I was -- this was a very important lesson for me.

One example is how she sought out information to purchase her own machine which pumps the excess fluid from her arm daily so that she does not have to keep going to the hospital. Another is her experience with the hospital and hospital physiotherapist:

I received a clean gown every third day, and a back rub twice in 10 days. On the eighth day I had a visit. (It gets better!) On the eighth day I had a visit from the physiotherapist and I mentioned that I could not lift my right arm. She proceeded to show me exercises to help my arm. Then she told me to join both hands in front of me. I did. My hands were below my waist. She enclosed my hands in hers and forcibly raised them almost to head level. A sharp searing pain crossed my chest. I looked down expecting to see blood. In total disbelief I looked at her and in a raised voice said: "You are crazy! You don't know what you are doing."

...Anyway, she did mention that the more exercise I did, the better it would be. And coming back to patients today...use your head! What she told me was absolutely wrong. ...Even when I was working, I would stop, I don't know how

many times a day and put my arm up...and let the fluid drain, and do a hundred exercises with that arm a day...at different times. You couldn't do a hundred at one time...I still couldn't do a hundred even today...but it was dumb, because what I was doing was forcing the arm to swell by over exertion...the arm swelled and without the lymph nodes the fluid was trapped and couldn't get out...and this is how I got the first edema.

While at the clinic one day, the head nurse approached me to ask if I would be willing to be interviewed by a student nurse writing a paper on oncology. She asked a few questions, the first was how I felt. After that, how I was coping with my situation, etc. Finally she inquired about the edema in my arm and asked when it began. I said: "A year after my surgery." She said: "That is very interesting, that's called secondary edema. Let me go and get the book." She went in the office and came back with a medical book. "Here, I'll let you read it. It says that secondary edema occurs when the arm is over worked." It didn't actually say "overworked", it used whatever the medical term which meant 'beyond it's capacity' I guess. And I said: "That's exactly what happened." And then, as I was young and naive...I thought that I would improve it...the more I did, the better it would be. Not so. I'm lucky that I can do many things with the arm, but there are some things that I just cannot do with it...and today I know that, and I don't over-extend...but back then I did not know that. I am able to play a pretty good game of tennis. And that is where my determination came in because I was blindly doing these exercises because I was going to work this arm out...not knowing that medically it was impossible to do it. But again that is where the determination in me came in, so I'm very happy...sometimes it didn't work out so well as in that case...But in a lot of cases my determination helped me.

Today her cancer is in complete remission and she lives an active, full life, and continues to be aware of the great gift of health she now has.

DENISE FOREST

Portrait of Informant

Denise Forest is Caucasian and was born in 1944, in Los Angeles. She requested her name be used in this research. She was married in 1962, in Juneau, Alaska, when she was 18 years of age, after one year of college. She separated in 1986 and divorced in 1990. She has seven children: a son, born in 1963, a daughter born in 1965, a daughter

born in 1967, a son born in 1971, twins adopted from Cambodia at 3 months of age in 1975, and a son born in 1976. She has two grandsons, one born in 1990 and one in 1993. Her religious orientation is pantheist and Taoist. Stressful issues from childhood included her having a mother who was an alcoholic and who was verbally abusive to Denise throughout her childhood and adolescence. Denise became a Born-Again Christian in her early adulthood, which was profoundly upsetting to her father who was an “intellectual” (her word).

She describes:

Then we went on to become missionaries in Japan, an interesting experience, but not financially lucrative, had another child, and returned from Japan in our 30s with four children, few marketable job skills and no home, bank account, or any of the material items people in our culture usually have in their 30s. We then proceeded to adopt two Cambodian children and I became pregnant again. We were very poor, lived in a rough cabin with a plastic roof, no electricity, an outhouse, no telephone. And my husband was away at work during the days so I had no access to an automobile. I have never seen anyone in this country living as poorly as we did. I found that difficult, but we coped.

The major stressor in life during the past decade has been:

. . . discovering and exploring my lesbian identity, which had incredible plusses but at the same time, because it led to the dissolution of a long standing family... And not just the relationship with my husband . . . but with all the family together, that was very stressful.

Denise teaches at a community college on Vancouver Island. She describes herself as trim, of average height, with short grey hair, and physically energetic. Other people describe her as healthy looking. She states she was overweight at the time of her diagnosis. Emotionally, she states she is fairly even tempered, calm, serious about her walks, and overly conscientious. She says she doesn't laugh readily, but does have a

sense of the absurd. She is distant with acquaintances, but enjoys playfulness and gentle teasing with close affiliates. Her strongest relationships are with her partner, her children, and one close friend. Her passions, she says, other than her lover, are her brilliantly diverse children, her walks, and long-distance walking in other countries.

Setting the Stage for the Ethnographic Interview

Since I was interested in interviewing as diverse a group of women with the experience of breast cancer as possible, I advertised in special interest newsletters. For example, I placed advertisements in some of the small specialty papers on Vancouver Island such as in the Victoria Sexual Assault newsletter, and the local Vancouver Island Lesbian and Gay newspaper. Denise responded from a small community in central Vancouver Island. After connecting with her by telephone and agreeing on an interview time and date at her home, I drove there and met with Denise and her partner one Friday evening. Whilst her partner continued making some delicious-smelling fruit conserve, Denise and I settled in the recreation room in comfortable chairs. We tested the recorder for sound and decided to place the tape machine on the arm of Denise's recliner chair.

Diagnosis

The date of Denise's original diagnosis was in August, 1993. She had been working on her Master's thesis in Education. Several days before she finished writing, she noticed a lump in her breast. After a visit to the doctor's, she was scheduled for a biopsy. The biopsy came back with a diagnosis of medullar cancer. Her surgery was scheduled within several weeks. She had the surgery on her breast and underarm; there were five positive nodes out of 38. Denise has changed her dietary habits by becoming a

vegetarian and reducing her fat intake to less than 10% daily; she has lost over 75 pounds. The chemotherapy, radiation, and terror of the experience, she states, also contributed to her weight loss. Now Denise exercises most days. She believes she has more energy than many others. Denise speaks of several unfortunate interactions with her surgeon whom she describes as “disempowering”, “pompous”, “rude”, “disrespectful”, and “patronizing”. The negative experiences with him has led to her searching in alternative medicine for more holistic healing processes. Denise has immense enthusiasm for life and is determined to make the most of however many years or months she has left. Her life, at the moment, is rich and full.

JANE

Portrait of Informant

Jane is a 41-year-old physician from New Zealand who married a Canadian physician. They chose to settle in the interior of B.C. They have three children, a 17-year-old son and two daughters, 15-years and 12-years-old. Jane created a medical clinic which specifically serves women with regard particularly to womens’ issues. As well, she is the manager of a thriving medical practice of which she owns a third. She and her family are active members of the United Church and they have an active social life. She and her husband are involved in Scottish dancing and the family skis together in winter. Jane is an enthusiastic gardener. As Jane hales from New Zealand, she had hoped originally, that as a family, they would all relocate to New Zealand.

Jane had been visiting her home in New Zealand a year ago primarily to be there with her family as her father was dying of bowel cancer. It had been a very stressful year

since Jane was taking a specialty post-graduate medical program, taking care of her three children and emotionally supporting her father and other family members. In her words:

I had been studying full time, the year I was there. Most of the time my husband was out working, so I had three children to look after. It had been a fairly stressful year around making the decision to come back to British Columbia (B.C.), which my husband really wanted to do and I didn't . . . We made the decision on what seemed fair for the family. We came back in the middle of winter.

Setting the Stage for the Ethnographic Interview

While advertising for candidates to participate in this research, I had approached Jane who has a medical practice devoted specifically to women and 'women's issues'. We talked professionally about women with breast cancer. I described my research goals. Then I explained I was looking for as varied a population of women with breast cancer as possible to cover the widest spectrum of possibilities. At that point, Jane then disclosed her own experience with breast cancer and volunteered to take part in the ethnographic study. I arranged with her to do the ethnographic interview at her convenience.

We arranged to meet at her home. Initially, she called to cancel due to the illness of one of her children. We re-booked the interview. Some weeks later I arrived at her home. Jane met me in the front drive which was bordered with very well cared-for flowers and shrubs. I later discovered gardening was one of her main hobbies. She piloted me through their spacious home to a sitting room which had a restful view out over the foothill mountains.

Of medium height and build, with blondish straight hair in a blunt short cut which framed her oval face, Jane appeared a little anxious. Her serious demeanor was somewhat

offset by her soft, hesitant smile. However, her calm, steady, forthright gaze and level tone invited me to start the business of the interview.

At right angles to the white wicker seat where Jane indicated she would sit, I set up the tape recorder and I sat opposite her in the proffered seat. Both of us sat quietly for a few moments and drank in the beauty of the view. After we spent some time chatting, Jane said she was ready. Her tissue box was handy and she found she needed it from time to time in the telling of her experiences.

Diagnosis

In response to the first ethnographic question, asking what her experiences after her breast cancer diagnosis were like, Jane responded:

B., my husband, and I went out for dinner. It was very special because it was Valentine's Day. And we had a really nice evening. I was starting to feel like, yes, I can cope with this. Because I'd had moments of doubt. Although I put my mind towards making it work once I made the decision to come back. But it didn't mean that there weren't times in the first few weeks we were back . . . It was cold and it was snowy. I was thinking, "Oh, this is hard." But we went for dinner. We had a really nice evening. And so, we made love when we came home..

. . . the next evening I thought, I must do a breast check. And so I was starting to do it lying in bed, when my husband leaned over and started to feel the breast. And I thought he was being silly, playful, and so I kind of laughed, pushed him away and said, "No, no, no, no. I'm trying to check my breasts." And then he said, "No, let me." I got annoyed and pushed him away, again. And then he said, "Well, actually, I thought I felt something last night. When we'd been making love." I just went rigid with fear.

And I think it was, I had this really bad feeling about it right away, which isn't really like me. I tend to be fairly optimistic about things. And so . . . It was really difficult to feel the lump. I did not feel that I would have felt it if he hadn't said something . . . and it was quite small.

Despite being a physician, Jane experienced many of the trials about the choices in procedures and treatments such as what kind of surgery, whether she should have radiation and chemotherapy, and if so, how much, etc., which the other informants experienced. She was able to utilize some control in that she chose the kind of surgery she felt best about. However, she experienced her physician husband's minimization and denial strategies as betrayal, particularly as her knowledge of her own body was compromised by what he omitted to tell her about the seriousness of her pathology report. Of course, she found out what the real situation was from one of her own doctors. She then felt much worse having believed her husband, who told her that her cancer placed her in a lower level of risk level than was indicated on the pathology report. She also experienced the cultural propensity for trivializing or discounting what she was experiencing as a breast cancer patient when her husband said that 'it would all be all right'.

Above all, the experience was terrifying for her in many ways, mostly because of the perceived cultural correlation between cancer and death. Her knowledge of cancer as a physician had no particular protective benefits. Jane appears healthy now. She is in remission, but has a strong mother lode of fear running through her since there is agreement in the medical profession that anyone who has had cancer is never cured. If there are no obvious signs of cancer, it is assumed to be in remission. It may reappear at any time in the future. Jane continues living her life to the full, active in sports, active in her home and work life, and continuing to promote breast cancer awareness by participating in such functions as running for breast cancer.

SUSAN HARRIS

Portrait of Informant

Susan Harris, her real name, describes herself as a 46-year-old Caucasian, single, who moved to British Columbia in 1990 to take tenure as a Professor at the University of British Columbia. Her specialty is Physiotherapy and she practices as a physiotherapist at Sunny Hill Health Centre for Children. She obtained her Ph.D. in 1980. She has no religious affiliation.

Excluding the period of time Susan was in active treatment with this illness, she usually jogs, runs, or walks three to five miles approximately four times a week. For over 23 years she has been jogging. She describes herself as healthy, fit, and relatively thin. Her mental and physical health has generally been good except for a major depressive episode in 1983-84. All her childhood, teen, and adult life has been affected somewhat by her father's more than 50-year history of manic depressive stress. A self-described workaholic who loves her work, she has published in many scientific journals and is heavily engaged in research with children.

Setting the Stage for the Ethnographic Interview

Susan Harris called me at the University of Victoria to investigate my research project in response to one of the flyers I had distributed at the Breast Cancer Breakfast, universities and hospitals in Vancouver. She was interested in participating in this qualitative research project. We agreed to do the interview at the University of British Columbia's Department of Medicine, in Susan's office. At the time of the interview, Susan had organized space in a small pleasant consulting room near her office. I set up

the tape recorder on the round table in the centre of the room and we sat at the table with the recorder between us.

Diagnosis

Susan is a clear, articulate speaker. She responded to my 'grand tour' ethnographic question in detail, with thick, rich description. She continued her story with very few interpolations from me. Her diagnosis of tubular adenocarcinoma was made on September 14, 1994. On September 23, 1994, she underwent a partial mastectomy and had daily radiation to her left breast through November and December 1994.

Susan states:

I've never noticed a lump. I've never had a lump. Mine have totally been on mammogram findings. That is interesting. There is a parallel between both my Wisconsin and my Vancouver experiences in that some physicians said it was a palpable lump and some said it wasn't . . . And that's a little disconcerting. The same thing happened in Vancouver. Two physicians said it was a palpable lump, and two said it wasn't. So it's interesting. But it was found on mammogram.

In 1994, I had been examined about a month before my mammogram by my family physician for a routine physical. And he had not noticed it. Nor had I noticed it, although I'm as unreligious as most women about breast self-exam. But the lesion this time was in the exact same place as the one in 1990, so those were micro calcifications. They were obviously a precursor, which the literature suggests they can be, which makes it even more inexcusable that this surgeon advised me to wait (for 5 years) until I was 50.

She went on to say:

The worst month in my life was the month I waited from August 15th till September 14th, which I think is an inexcusably long time. Until I had the definitive biopsy results I waited one month. This was also different than the Wisconsin experience. There I had the mammogram, heard about it the next day, was in to surgery by the next week, had the results within 2 weeks. So my 'not knowing' period was at the most two weeks long, two and a half weeks. In Vancouver I had the abnormal mammogram. It took 3 days for my physician to call. It took another week to set up an aspiration biopsy. That was inconclusive. It

was either fibroadenoma or adenocarcinoma. Again, my family physician called me, said, "It's either this or this." At first it was, well, 80% of mammograms are normal, so I was sort of--80% of atypical mammograms turn out to be okay, so first I was playing with 80/20 odds. Then my family physician said, "Well, it's either adenocarcinoma or fibroadenoma." And I thought, "Okay, now I've got 50/50 odds."

Then I went and bought Dr. Susan Love's Breast Book and read:

"Fibroadenomas typically occur in women in their teens and early twenties." And I thought, "Why didn't my family physician tell me that? Why are we playing this game that I might have a fibroadenoma when I'm 46, which is pretty unlikely?" So then I was sort of thinking 50/50 odds, but really in my head thinking, "It's really unlikely that it's a fibroadenoma."

Susan continues the description of events:

. . . the radiologist, the diagnostic radiologist at the cancer agency, who was also a woman, was the worst physician with whom I have come in contact. She did not explain what has happened. The radiation tech--and this is the most barbaric procedure that I've had yet, is this core biopsy, because you lie on a table in prone position with an opening with your breast hanging through the table, and they put your breast in a mammogram-like contraption. They give you a little local anaesthetic. They tell you that you may feel a throbbing. They shoot in a--like a little guillotine that pulls out a plug of tissue. Well, when the first one went in--they say you'll hear a bang, and that's about all they say. The radiation tech was wonderful. She explained everything.

The physician came in, kept referring to me as Mrs. Harris, even though it said on my card that I was Dr. Harris, never really introduced herself, never introduced the Resident doctor. I was already laying down face down in a compromised position. They told me that they were going to shoot this little bullet four times.

The first time it went in, it was excruciating pain. My legs went off the table. The radiation technologist said, "You'll feel--you might feel a throbbing." And I said, through tears, "This is not what I would call a throbbing. This is fairly intense pain." At which point they gave me a little bit more local anaesthetic, but they didn't really wait for it to take effect. The second one wasn't too painful. The third and fourth were equally as painful as the first. And I would say that of all my experiences, including surgery and post-op, that was the most painful.

I don't think that should have to be. The nice radiation technician explained to me afterwards that there are several different physicians that do this procedure. That there are others that take a lot longer, but you might be there two hours, but they

at least wait until it's numbed. And if she had her druthers she'd rather go with the quick and dirty. And I thought to myself, "If I had my druthers, I'd rather go with something between the two."

This woman never introduced herself, this physician. The only time she talked to me face to face, they sat me up after this procedure. My breast was bleeding. She stood at me--she was very short; I was sitting on the gurney--she stood at me so her eyes were level with my breast and talked to me as I was totally disrobed with her male physician. And I'm not--because I'm a health care professional--I'm not a terribly modest person. But there was no attempt to drape me, to give me back any of my dignity. I also heard her mumble something to the Resident about, "See this here," which I knew was probably something negative, but she didn't share any of that information with me. So that was by far the most negative of my experiences.

Susan was finally given the diagnosis of a 2 cm tubular adenocarcinoma.

Anyway, the surgeon shared this whole plan with me based on the size of the tumour and that is the bench mark. It didn't have anything to do with whether or not the nodes were negative at that point because they didn't know. But the size of the tumour was the bench mark here in B.C. as to whether or not I would have chemo or not.

Based on all the reading I had done before I met with the surgeon, I figured, based on the fact that tubular adenocarcinoma is a very less aggressive type, it's very rare, but it's a really good kind to have, based on everything I had read, and I had read a lot. I had been to the medical school library. I have read not only textbooks but primary references. Everything I had read, I figured out that I would probably have a lumpectomy, followed by radiation. I was not expecting to hear chemotherapy. When I heard on September 16th, a week before surgery, that I was going to have chemotherapy, I really fell apart. And if you listen to the tape you can hear my voice trying to hold it together. I did not expect the chemo part. That took me a couple of days to bounce back from. But then I finally wrapped myself around that and decided, yeah, it was great to do everything possible. Some of my friends who were breast cancer survivors said: "If they hadn't ordered chemo, we would have told you to advocate for it."

So I went from not thinking I would have chemo, to being told I would have chemo, to falling apart, to then accepting it and to deciding that was the best course because I would zap this thing to kingdom come.

Then I had surgery and the tumour was smaller than they expected. There was no lymph node involvement. There was no lymphatic or vascular perineural

(glossary) invasion. And the surgeon told me one week after surgery that I probably wouldn't have to have chemo. So I went from thinking I wouldn't have chemo, to being told I would, to falling apart, to wrapping myself around it, to deciding that this was the best course, to then having the chemo taken away. Half of me, after having read about chemo, wanted to have the chemo taken away, but half of me had risen to the occasion and wanted to do everything possible. Then I set forth and read everything possible about pre-menopausal node-negative women and the pros and cons of chemo and the 1990 National Cancer Institute's call that all Stage I node-negative women should have chemo anyway if they're pre-menopausal . . .

And so then it was another two and a half weeks before I met with the--actually, it was three weeks before I met with the people from British Columbia Cancer Agency (BCCA). And I had decided I was going to go ahead with the chemo. But as I got closer to that time I got more and more cold feet about going through that. And everything I read was equivocal. Everything I read said women with my various set of circumstances were in a gray zone. I wasn't in the group that definitely needed chemo, I wasn't in the group that definitely didn't. I was in the group on whom you would do clinical trials to see what was effective. And I'm a researcher, so I was open to being part of a clinical trial.

Susan Harris continued to find ambiguities and differences between what was happening for her and what was written up in the medical journals and books. She and other breast cancer survivors who do their own research have found that there are differences between countries, cities and even doctors in the same hospital on how to treat various stages of breast cancer. Armed as she was with all the primary research sources, the medical library books and being herself a faculty member of UBC's Department of Medicine, she still found few straight answers. Susan was able to proceed through the "roller coaster" (her term) of this experience and still discuss the positive changes in her own life.

CHAPTER 5: ETHNOGRAPHIC ANALYSIS

Everything is difficult at first (Kopp, 1979, p. 21)

The raw data of interviews are the actual quotations spoken by interviewees. There is no substitute for these data (Patton, 1990, p. 179).

Analysis involves working with data, organizing it, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned, and deciding what you will tell others (Bogdan & Bilken, 1982, p. 145).

Ethnographic analysis is an instrument for uncovering meanings in a culture. It is a strategy for helping us understand ourselves and each other. Ethnography asks, "What is this or that kind of experience like?" (Van Manen, 1984, p. 37). Culture is a system of meaning-making amongst the individuals in that culture. We make meaning out of our experiences, often unconsciously, a majority of the time. Meaning is relational and contextual. I see a person waving her arm and I think that she is waving hello, or good-bye, or to attract someone's attention, depending on the context. I interpret certain decorations to mean that Halloween or Christmas is approaching. A baby is crying, sending a signal which the adults must decode. One adult might interpret the cry as an irritating intrusive sound; another adult may feel that the baby is hungry; another may feel the baby is tired; and yet another person might interpret the cry as part of a normal settling down period before sleep. Ethnography explores alternative realities of others by entering into the world of those individuals. The ethnographer interprets the realities of others, which have been described in the informants' own words. An assumption of ethnography is that the study and interpretation of language can illuminate meaning in a culture.

In order to understand our world we sort and classify things. In order to make and discover meaning, children in all societies learn to understand verbal and nonverbal symbols. Although children do receive some explicit teachings, or instruction, much of

what they learn is tacit, or learned from experience. This is the condition present in all new situations, not only applicable to children, but to all naive individuals. As a new student at university, for example, I found the 'old timers' knew much more about how to live on campus than the 'newcomers.' Some things I discovered by myself, through experience, whereas learning how to use the library was facilitated by going to the local expert, the librarian. When investigating other cultures or subcultures, ethnography has tools such as questions and analyses for reducing the learning time, and for finding out both tacit and explicit knowledge.

Analysis is an investigation into the component parts of some subject. All aspects of life are organized into bundles of things; for example, sounds are bundled into language, and symbols are bundled into deeper meaning. Using Spradley's (1979) method of ethnographic interviewing, and beginning with a perspective of not-knowing, I interviewed women with breast cancer. At the forefront was my concern about the cultural bias of silence surrounding illness. Ethnographic questions were used in all my interviews as tools to facilitate the gathering of information. Three kinds of questions were utilized to gather data for the ethnographic analysis: 1) descriptive questions, 2) structural questions, and 3) contrast questions. These three types of questions were asked in the flow of the interview process. They were often answered concurrently. Systematic analysis of words, phrases, sentences, and metaphors/images derived from the responses facilitated my interpretation of the participants' language and symbols into meaning for myself and others.

Descriptive Questions

The objective of descriptive questions is to encourage the informant to talk in order to draw forth a large sample of the individual's language. I discovered that sometimes a single descriptive question could result in an informant talking for quite a long time,

sometimes until the tape ran out. And even then, occasionally an informant would simply keep describing her reality. Generally, after setting the stage, I would ask open questions such as: “Can you tell me what it is like to have a diagnosis of breast cancer?” or “What is it like for you since the diagnosis of breast cancer?”

After establishing rapport, and asking the first open question, I listened while Anne Marie explained in detail what the diagnosis was like for her:

My worst time of this whole thing, now occurs. Because I had that done on a Wednesday, Dr. Clay, at the end of the surgery, when everything was finished, and I was going to be wheeled back and put in to the recovery room, said, phone my office on Friday and we will see if we have the results.

So, that's fine. I've got that in my head now, this is very important. So, of course, on the Friday, I've taken my Thursday as the recovery day, and Friday's the phone day, and it's THE Friday. I phone him. "Oh yes, Mrs., I don't think we've got the results." This is the secretary: "I don't think we've got the results yet, but I'll make sure that the doctor calls." So that's great. Meanwhile, I wait at home. And I wait. And I'm getting more anxious and thinking, "What's happening? Have they done anything? Shall I call back?" And I thought, quarter to five and I'd phone back and say, "Is there anything?" Because I know it's Friday, and I'm going to be anxious the whole darn weekend. When I phoned back, it was the answering system, the office is closed. I thought, "My God ..."

So I'm frantic. There's nothing, there's no way I can get results, because I can't phone the Cancer clinic and say, there's no way, you can't get them. I thought, "There's no way. I can't contact anybody. I can't say to the answering service, "Would you mind paging Dr. Clay?" Would he go back and look it all up? I thought, "Okay, I'll go to work on Monday." I'm finished early Monday, as I work 7 to 3. I'll call the office again when I get home. So I called the office on Monday. Same story, we didn't get the results, but Dr. Clay will call back, so just wait. I wait, and wait. I phone again, and the office was closed again.

By about this time, I'm about ready to click. I'm thinking, "Tomorrow, I will nab them." And I go into work, and I go through the same process of thinking. I want to get my results. I decide I'll wait till I get home, as I can sit at the phone. I won't be bothered by anybody at work, and I have to drop off at a shop on Fourth Avenue first, to pick up something.

I do, I get out and my car won't start. So I'm thinking, "I want to get home and get this call." I call BCAA, get the car started, it's the battery. I get home, and he says, "Leave the car running because it needs to charge." I leave it running on the street. I come in, because my major concern is still, do I get the results? I phone. "Oh, Mrs., I'm sorry, no, we haven't, we'll have to get Dr. Clay to phone you back." I'm here, I'm afraid to even go and get my car that's running on the street, because I'm so anxious to get this call. I'm just about flipping. And I wait,

and I wait. And I think, "I've got to phone back earlier this time." Do you know what? They'd gone again!

At that point I put down the phone and I just burst into tears! I'd just had it. I thought about the car still running on the street. I've got to go get it. I haven't heard a word. They've done it again to me. This is my third time!

I must admit, I just went into, I dissolved. And then I guess my dad caused problems, and I said, "I can't help. I'm finished." I had a friend who is an oral surgeon who actually knows my surgeon. And he said, "You've just been through too much. It's really bothering you now. We've got to do something about this." He said, "I'm just going to phone him at home and say, "Dr. Clay, do you realize what is happening? I don't think you know what's going on with your staff." Because doctors always have a front person there who is their block, who protects them. So, it was really the fault of the secretary, not to push him, not to say, "Look, this woman has been waiting . . ." She should have known.

So, he did call him, and when he talked to the surgeon, he said, "Oh, I have the results, and I'll phone her at home then." So Tuesday night, he called me. But the reason why this oral surgeon had phoned was because he was leaving the next day, early, and he wanted to know what the results were, too. In fact, by the time Dr. Clay had called me at night, it was late. I didn't want to phone my friend because he was getting up so early in the morning. I knew he was going to be asleep, so he didn't know by the time he left. So he was kind of on tenterhooks wondering what had happened. So we were both, alike.

Anyway, so he finally got through, and Dr. Clay did apologize, and said he had really not got messages from his secretary and that he would have got back to me and so on. But she had neglected me because the results hadn't got in. She didn't tell him to get them and it was just an error that went on, and on.

Because they were there that day, on the Tuesday. So we went through that and I think that was my worst. And I just think that women are out there waiting for results, or anybody with the diagnosis of cancer, that you are frantic when you have to wait longer and longer.

You've got to know one way or the other because of what has to happen next, and of course, when you are told, you've got to make decisions. They should be able to tell you soon enough.

If the descriptive question does not result in an adequately large sample of language, additional data can always be elicited by asking clarification questions. For example, in an interview with Yolande, I asked her to clarify one of her statements further:

Interviewee:

I don't think that you are ever free of the fear that if something happens physically to you that it might be cancer, and I think that is reinforced by the physicians themselves.

Interviewer:

And how do they do that?

Interviewee:

Well, this is an example. I had found that I had a lump in my throat. My sister had noticed it one time when I was out here visiting. So I went to the doctor and she sent me to an endocrinologist and having a history of cancer they were worried that I might have cancer of the thyroid. I didn't. Then I had a problem with colitis, which I still have, I haven't had an episode for quite some time, but then there was the concern that I might have cancer of the colon. Then there was another episode. I had a, after I had been through menopause, I had this terrible, terrible pain, and lump in my pelvic area and they were concerned that I might have cancer of the ovaries. So I had a hysterectomy and it turned out that I did not. I had a mass that was big, but it was benign. So every single time that I have had anything medical, there was concern . . .

Rapport had already been well established between us. Yolande acknowledged me as the naive student, and accepted her role as the knowledgeable person. Yolande demonstrated her expertise by explaining: "This is an example." As more information was shared, further questions, both descriptive and clarifying, were posed and more information was gathered.

Structural Questions

The objective of structural questions is to gather information on everyday life: "What kind of vehicle do you have?" "What kinds of flowers are you going to buy for the garden?" Structural questions often ask for an explanation. An example from an interview with Elaine Zyri is:

Interviewee:

I had so many stresses in my life.

Interviewer:

I'm interested in your stresses. Can you tell me more about what kind of life stresses you had?

Interviewee:

Oh yes. You name it, I've had it. Physical brutality from childhood and from D. Emotional and psychological stress from work, husband, D's kids. The divorce, breakdown, cancer.

Elaine then went on at length to describe each of these stresses.

The premise behind the use of structural questions is that they elicit similarities between and among symbols. In turn, this principle of discovery leads to new perceptions of meaning. Informants' knowledge is contained in basic units of meaning called domains (Spradley, 1979). Structural questions assist the researcher in locating domains, which informants use to describe their realities. *Contrast Verification* questions are another form of structural question. These questions verify meaning with the informant by clarifying and so ensuring that the researcher is not "translating" into her own language. Both domain analysis and taxonomic analysis are based on this underlying principle of seeking out similarities. A Contrast Verification question asking for clarification may bring forth a great deal more information:

Interviewee:

I just got spunky lately. That's what I meant by being a rascal. I am a rascal.

Don't listen, don't listen to the medical profession and don't listen to anybody. Oh, shit, do it your way. If you want, okay, it's your body and it's your life and it's your choice. Oh, do it your way. Oh, yes, don't get pushed around by anybody. You've got to be your own person and your own master of your destiny.

I couldn't make up my mind this last time when Dr. Gelman told me that I needed Taxol, and the decision was mine. And I couldn't make up my mind, and I thought, "Well, what have I got to lose? I only have my hair to lose." So anyhow, I've taken the Taxol and I'm really glad that I did. It was my decision as to what I'm going to do. So if some people have to do it their way, then they have to do it their way.

Interviewer:

So would you say there was any particular example that you would want to give, that you wish you'd been more spunky about?

Interviewee:

I don't think I would have had a mastectomy. I think I would have had a lumpectomy, because it's very sad to lose your boob. You're so bent out of shape when you're told that you've got cancer and you have to have surgery. And I spoke to Dr. Alexander and he said because of the way that the cancer laid, I had to have a mastectomy. But I think I would have rather have had some of it left. I would have asked for radiotherapy of my nodes rather than not having them, because I feel that if I had had that, I maybe wouldn't have so many problems with metastases now, because I think I was either five or seven nodes positive. I can't remember.

But I think that it's better to be your own master of your destiny, to read over your chart, to talk to the different people and to get a second opinion, and to really think this through, because this is something that's going to last for you for the rest of your life. This is not going in and getting a big toenail taken off. No, once your boob's gone, that's it. You don't grow it back.

Contrast Questions

Contrast, as a principle, demonstrates that meaning can be uncovered by finding out how a symbol is either the same as, or different from, other symbols (Spradley, 1979). Ethnographers look for similarities among symbols, attempting to detect them the same way informants do. Similarity is the flip side of contrast. Some symbols are within a boundary (a tuna is a fish), others are outside the boundary (a whale is not a fish). Distinction in meaning follows from a symbol's membership in a contrast set, which is a delimitation on what a symbol means and what it does not mean. A kitten is a member of the animal world. A puppy is a member of the animal world. They both belong to the set of young mammals. However, a kitten is not-a-puppy. The puppy is not-a-kitten. The differences in meaning come from membership in different contrast sets. Both are young animals, but each belongs to a different group, feline or canine. Language and meaning comes from repeatedly sorting symbols into bundles of more and more specific

differences and similarities. Contrast questions follow the ethnographic goal of posing questions so that informants may go on and describe their world in their own way.

One common trend that appeared during most of the interviews was the informant's initiating descriptions of contrasts. These contrasts often contained information about 'before cancer' and 'after cancer,' and about an individual's behaviour changes after the diagnosis and treatment of breast cancer. For example, Sharon tells about before and after she had acquired her prosthesis:

I have a prosthesis, and I'm very happy with it. It really wouldn't bother me to lose the other breast, if it meant I could live. So that's how I feel about my breast. Now I think he (my husband) would feel a little more differently about it. I think, breasts are more important to him, but they're not to me. If I can have my life, then I can even have a second mastectomy . . .

Before I got it, I was wearing one that the Reach for Recovery woman had given me. I was downstairs in our lobby working on a Christmas poinsettia display. I waited a while before I got it. I wanted the scar to heal, and I was working with the poinsettia plants and we were putting them in the shape of a Christmas tree in our apartment lobby. And all of a sudden I looked down and I realized that I had this breast down here by my belly button, and one up here, and I said, "Oh my goodness!" So after that, I learned to pin it into my brassiere. This was December, and I'd had the breast removed in June, but I went shortly thereafter and got the prosthesis. I'm very pleased with it, because it's nice and heavy so it stays put. I haven't had any problems with it popping out.

Denise Forest explains about some differences (contrasts) she made in her life after breast surgery:

I worked really hard in terms of getting myself healthy again. So when I was in hospital I got up and exercised. The kind of food that they feed people absolutely appals me . So I had people bringing stuff in to me . . .

I had already done a fair bit of research around diet and so on, so I was making some radical changes from the day that I got the diagnosis. I went from eating a lot of sugar and a lot of fats and a lot of caffeine to a vegetarian diet. And I did some research and found that, not so much in the west, but in, particularly in eastern Europe and the Soviet, they are doing quite a bit of research with restriction of fat in the diets of persons who have been diagnosed with breast cancer. So I've cut my fat intake down to less than 10%, and I keep it there.

Components of meaning are often identified by differences. In the example above, Denise was clarifying differences in her lifestyle after her diagnosis and surgery. In contrast to before her surgery, afterwards her behaviours were geared toward health and were reflected in a concrete difference such as weight loss. She went on to explain that her body change was not entirely due to her food choices. Although some of it was due to treatment, she reiterates that some of it was a result of changes to her diet.

I have lost 75 pounds. Initially it was terror. And I was unable to eat. Then it was the chemo. I reacted very strongly to the chemo. And then following that, the rest of it I would say has all been my dietary changes.

All members in a culture categorize time, places, steps in a process, objects, persons, and most other things in their world in order to standardize, simplify, and clarify meaning. We all organize information so that it fits into categories we have previously learned. Some aspects of our culture are changing so quickly that it becomes difficult to categorize specifically, so we resort to global categories. For instance, a few years ago, I had no idea what a modem, a laptop, or a PC was. Now I am more enculturated into the use of computers and I no longer need to worry about how to categorize 'e-mail' and 'snail-mail.' I have *learned*. I own and use a computer. I have begun learning the language of the computer culture.

After their initiation into the culture of those who have breast cancer, the informants continued to learn both new language and new behaviour associated with this different state of being. Ethnographic analysis examines the ways in which informants use language and seeks to understand the ways language is organized into units of meaning, or domains. Exploring ways that domains are similar and different is one aspect of ethnographic analysis. Domain analysis and three others, Taxonomic analysis, Componential analysis, and Theme analysis are the primary analytical methods used in this study.

Domain Analysis

. . . I search for the philosophers' stone. I know it is there, hidden in the deepest, dampest cul-de-sac. It awaits discovery. To find it would be like the harnessing of fire. It would illuminate the world. Such a quest is not without pain. Who can gaze on so much misery and feel no hurt? Emerson has written that the poet is the only true doctor. I believe him, for the poet, lacking the impediment of speech with which the rest of us are afflicted, gazes, records, diagnoses, and prophesies. (Selzer, 1976, p. 16).

An ethnographer is usually neither a poet nor a doctor, but she or he gazes, records, and interprets what is seen after applying ethnographic methods to the narratives of the informants. To begin the analysis, the ethnographer seeks symbols representing domains in sections of narrative and Domain Analysis Worksheets are used to record domains (see Figures 1 and 2).

The first component in the structure of a domain is a *cover term*. Cover terms are labels for categories. All domains have at least two and probably many more *included terms*, and each category has boundaries to contain all included terms within that cover term. Categories are governed by the *Semantic Relationship of Strict Inclusion* which both defines all those things which are in the cover term and excludes those things not in that cover term. For example, the cover term 'trees' includes all trees, but not bushes. Included terms often have many more *terms within included terms*. All languages have ways of sorting components of language into meaning. Decoding cultural symbols is only part of the task of finding meaning.

Another major part of the task is finding the relationship of any symbol to other symbols. All domains have a single *semantic relationship*. All human languages sort clumps of meaning by using semantic relationships. Using the example from Spradley (1979) of the Big Dipper in the night star system, I can look up at what appear to be individual small points of light in the night sky. It is when I look at a specific cluster of stars and see the relationship amongst those stars that I become aware of the pattern and

meaning of the Big Dipper. It is the pattern formed by the relationship of those stars to one another which gives me the image of the Big Dipper. In the same way, it is the relationship of one symbol to another which results in meaning within each culture. It is ethnography's task to identify the components of the cultural symbols and to then search for underlying meaning by seeking the tacit or explicit coding rules. Uncovering the relationship among cultural symbols in turn uncovers meaning. In all languages, there are only a limited number of semantic relationships (Spradley, 1979). A list of Universal Semantic Relationships is presented in Appendix E.

In doing the initial domain analysis, I reviewed each paragraph in each informant's narrative looking for folk terms/cover terms. Next I searched for the relationship of the included terms to the cover term. Domain analysis facilitated the isolation of individual units of cultural meaning as demonstrated by the informants' interviews. Domain analysis of all the interviews resulted in an large amount of data and information. The next step in the analysis was to move toward a more in-depth analysis of a limited number of domains using taxonomic analysis.

Taxonomic Analysis

Interviews with informants covered a broad number of topics resulting from the open-ended questioning style. An organizing principle in every culture and language is inclusion. For an example, see Figure 3, Making a Taxonomic Analysis of Large Inclusive Domains. Meaning is created by learning which terms are included in which classification sets. Oak and maple are trees; spruce and pine are evergreens. These are examples of inclusion; they tend to become automatic parts of speech patterns to the native speaker. For an example of a Taxonomic Worksheet demonstrating semantic relationships of strict inclusion, see Figure 4.

The need for a holistic, or general picture, for the audience of this research is balanced with the need for an in-depth analysis of a restricted subset of the domains. A taxonomic analysis illustrates the relationships among all the cover terms/folk terms in a domain. For example, a schematic illustration of the taxonomic analysis of loss is presented in Figure 5. The cover term 'Loss' has many included terms and some terms within included terms, all of which combine to describe the single semantic relationship of 'a kind of' loss.

An important feature of taxonomic analysis is that it has many different levels, from the general to the more specific. This hierarchical organization is illustrated in Figure 6. with 'feeling my whole world had crashed' based on the semantic relationship of spatiality: X is a part of Y. To look further at the more specific aspects of meaning, I performed a componential analysis.

Componential Analysis

Taxonomic analysis emphasizes isolating a single semantic relationship. Componential analysis, however, emphasizes isolating multiple semantic relationships between the cover term and other symbols. Ingredients of meaning associated with cultural symbols can be systematically uncovered by using componential analysis. Attributes or elements connected to a cultural symbol are revealed. Componential analysis takes contrasts and organizes them into a system clarifying meaning. Some attributes and semantic relationships of 'crazy-making', a part of 'feeling my whole world had crashed' are shown in Figure 7. The attributes of 'crazy-making' (cover term) are connected by several different semantic relationships such as 'is a cause of.' 'is a part of.' and 'is a way to.' These semantic relationships help to define the cover term 'crazy-making.'

A Paradigm Worksheet for the componential analysis of Reasons for Experiencing Fear is shown in Figure 8. The domains are entered in the left hand column. Attributes are listed across the top. With a number of paradigm worksheets, connections of meaning can be observed between each paradigm and other domains. Each informant has many such cultural 'maps,' all forming a complex set of systems of meaning. These maps of categories coming from the narrative data contribute to theme analysis. Themes arising out of the informants' stories describe some essential aspects of living with a diagnosis of breast cancer. Discovering cultural themes suggests that there are universals in the holistic picture. Theme analysis will be considered next.

Theme Analysis

Configurations of meaning emerge by comparing, contrasting, and classifying small units of collected narrative data in ethnography (Fetterman, 1989). These small braids of meaning become woven into larger and larger patterns of meaning as the analysis proceeds. Cognitive maps are built using cultural themes. A theme is something people conceive of as truth, part of the system of symbols in a culture. It is an assumption about some cultural aspect of an individual's thoughts or behaviours. Themes have differing degrees of generality and they emerge in more than one domain. When I observed that a single concept or idea appeared in several domains, I noted the possibility of a cultural theme. Strategies for discovering cultural themes are: componential analysis; domain search for ordering each informant's experiences; and schematic representations of sections of each informant's knowledge. Discovering cultural themes by visually noting the organizing aspects of each informant's cultural depictions are shown in Figures 9 through 17. The themes emerge clearly from the collected narrative data, yet are themselves often referred to only tacitly. The cultural scene of breast cancer integrates these cultural themes tacitly: Dehumanization; Disempowerment and Trivialization;

Shame and Stigma; Coping; Minimizing and Denial; It (cancer) Changes Everything; The Game of Survival; and, Doctor is God and He Takes Charge of Your Life. Explicit cultural recurrent themes evident in the breast cancer cultural scene (see Figures 19-22) are universally described by all informants in this study: Adaptation to Ambiguity and Stress; Sadness and Anger; Fear and Terror, and Lack of Support.

When an idea re-occurred over and over again in the collected narrative data across all informants' interviews, I began to see patterns as to how these cultural themes connect and define the subculture of those who have breast cancer. It was a specific research demand that individuals selected for this research be as diverse as possible so as to access as wide a cultural pool of information as feasible. Themes act to weave connections of one cultural scene to another as general semantic relationships among domains. One of the strategies for exploring the data for themes is to do an inventory of all the images and metaphors employed by the informants (see Figure 18).

Theme analysis across domains and images revealed the existence of four major recurrent themes. These themes occurred steadfastly across various situations in the context of having breast cancer. When themes recur extensively across domains, metaphors and all clients interviewed in a specific cross-sectional ethnography, they may be considered as universal cultural themes in that study (Spradley, 1979).

The first and most dominant theme appearing over and over again in this ethnography was adaptation to stress: the need for each individual informant to adapt to the ambiguities inherent in the realities of having a diagnosis of breast cancer. The universal cultural theme of Adaptation to Ambiguity and Stress is shown in Figure 19. The second universal cultural theme incorporated aspects of both Sadness and Anger (see Figure 20). The third universal cultural theme, illustrated in Figure 21, was Fear and Terror. The

fourth universal cultural theme shown in Figure 22 deals with informants' experience of Lack of Support.

Universal, i.e., universal within a specific culture or subculture, themes demonstrate the realities faced by individuals in that culture. By analysing cultural themes in the culture of those with breast cancer, I wanted to bring to light some of the issues faced by this population. It is my intention that the tacit cultural themes and the explicit universal cultural themes be drawn together to create a counselling tool for those working with breast cancer clients. These themes represent a rich resource of information which can be utilized to inform all those living and working with those who have breast cancer. These themes very poignantly describe the informants' experiences and go a long way towards 'teaching' the researcher and the reader 'what it is like to have a diagnosis of breast cancer.'

Chapter 6 will follow with a discussion of the tacit and explicit themes and how they can be incorporated into counselling and teaching tools.

Figure 1. Domain Analysis Worksheets. Informant # 2 (Elaine Zyri).

July of 1990, I noticed a lump on my breast, but I ignored it until December when I went to my GP in Nanaimo, who I went to school with, and he said, "Elaine, I think you've got a lump in your breast and you have to have a mammogram", which I did, and then after that I saw the surgeon and then I had my biopsy and the surgeon told me it was malignant, so I started on the path of having breast cancer, but I think I got here through stress and not knowing how to cope and not knowing how to deal with stress, and not knowing how to ask for my own needs, wants and desires to be fulfilled, and I also came from a very brutal dad and my mom was very busy putting kids' fires out and didn't have time for us, so we were sort of left in limbo, it was a pretty horrendous upbringing. Anyhow, to get back to it, so I would say that my breast cancer is due to the stress of my life in not knowing how to cope with it, and I think my ongoing recurrences are that, also, because it's been very stressful living in the house where I'm living, I don't get very much support and I try the best I can not to get involved with what's going on there, but it does, in some way, affect me. And I would have moved out this summer after Darrell got a little heavy-handed with me, but I ended up having another reoccurrence, and I couldn't see moving out on top of all of that, but I am planning on leaving this situation some time once my health gets sorted around. I think I would say that my breast cancer is basically due to a suppressed immune system and not learning how to cope with stress properly.

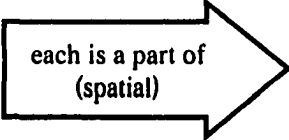
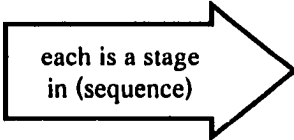
Included Terms	Semantic Relationship	Cover Term
<ul style="list-style-type: none"> - I got here through stress - not knowing how to deal with stress - not knowing how to ask for my own needs, wants, and desires to be fulfilled - I don't think that people like me who get breast cancer basically have come from a family where they threw roses after you when you left home. I think we're limping ladies and the immune system got into trouble - I sort of picked up the pieces, got everything done, and unfortunately got very sick with another metastases 		<p>Living in a cave, very sad and lonely and very unhappy</p>

Figure 1. Domain Analysis Worksheets. Informant # 2 (Elaine Zyri). Continued.

Included Terms	Semantic Relationship	Cover Term
<ul style="list-style-type: none"> - July, 1990, noticed a lump on my breast - Dec., 1990, went to GP - mammogram - saw a surgeon for biopsy - surgeon told me it was malignant - mastectomy (sad to lose your boob) 		The path of having breast cancer

I don't think I would have had a mastectomy, I think that I would have had a lumpectomy, because it's very sad to lose your boob. You're so bent out of shape when you're told that you've got cancer and you have to have surgery, and I spoke to Dr. Alexander and he said because of the way the cancer laid, I had to have a mastectomy, but I think I would rather have had some of it left, I would have asked for radiotherapy of my nodes rather than not having them, because I felt that if I had had that, I maybe wouldn't have so many problems with metastases now, because I think I was either five or seven nodes positive, I can't remember. But I think that it's better to be your own master of your destiny, to read over your own chart, to talk to the different people and to get a second opinion, and to really think this through because this is something that's going to last you for the rest of your life, this is not going in and getting a big toenail taken off, no, once your boob's gone, that's it. You don't grow it back.

Figure 1. Domain Analysis Worksheets. Informant # 2 (Elaine Zyri). Continued.

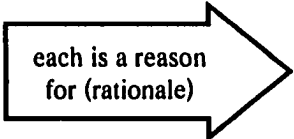
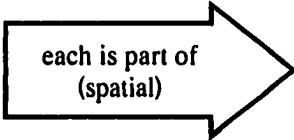
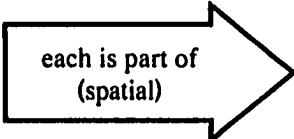
Included Terms	Semantic Relationship	Cover Term
<ul style="list-style-type: none"> - my father was brutal when we were growing up - there was a lot of verbal abuse, and physical abuse, and physical deprivation - I left home too early - I wasn't prepared for being out in the world - I hadn't been socialized into what was expected of me - stress of my husband leaving me - he divorced me for a younger woman - nervous breakdown - moving into a family that had teenage girls that I didn't know much about 		Always had a certain sadness
<ul style="list-style-type: none"> - came from a very brutal dad - my mom was very busy putting kids' fires out and didn't have time for us - so we were left in limbo 		Pretty horrendous upbringing
<ul style="list-style-type: none"> - to be ignored - be bought off with money - D got bent out of shape and got really nasty - beat me up - in a Transition House for five weeks - no one asks me how my day's gone - or what I have done 		Not having support when you're going through this

Figure 1. Domain Analysis Worksheets. Informant # 2 (Elaine Zyri). Continued.

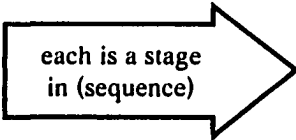
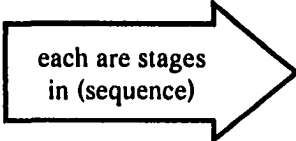
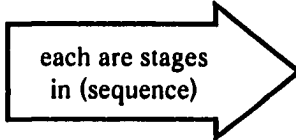
Included Terms	Semantic Relationship	Cover Term
<p>Treatment:</p> <ul style="list-style-type: none"> - originally chemotherapy (cmf), now Taxol every three weeks (for control, not cure) 	 <p>each is a stage in (sequence)</p>	<p>The path of having breast cancer</p>
<ul style="list-style-type: none"> - 1st metastasis - lung - 2nd metastasis - right hip - 3rd metastasis - spine - 4th metastasis - lung again - back on radiotherapy 	 <p>each are stages in (sequence)</p>	
<ul style="list-style-type: none"> - I'm a mouthpiece - I don't answer to anybody, to any degree anymore - I've taken over control of my life, actually, if people don't like it, it's tough 	 <p>each are stages in (sequence)</p>	<p>Being master of your own destiny</p>

Figure 2. Domain Analysis Worksheets. Informant # 5 (Laura).

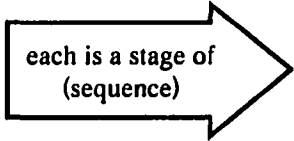
Included Terms	Semantic Relationship	Cover Term
<ul style="list-style-type: none"> - April 25, I was taking a shower when I noticed a hard thing - had it for 2 months before saying anything - when I was speaking to my sister, I told her about discovering this lump in my breast - she told me to check it out - family doctor told me that since it didn't hurt, it was cancer - appointment for a mammogram - specialist said we have to work on it right away - did a small operation - did a biopsy, but it didn't show up as cancer - told me I was going for an operation - if it was cancer, he would take the breast off - when I woke up after the operation and saw no breast then, I was crying - Dr came the next day and said it was huge, it was spreading so fast - in hospital just 2 days - tests - ultrasound, bone scan, blood tests - started radiation 20-23 August, 25 sessions and chemo now (Sept 95) - goes for 6 months 	 <p>each is a stage of (sequence)</p>	<p>My whole world fell apart</p>

Figure 2. Domain Analysis Worksheets. Informant # 5 (Laura). Continued.

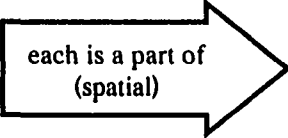
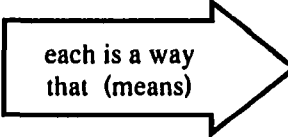
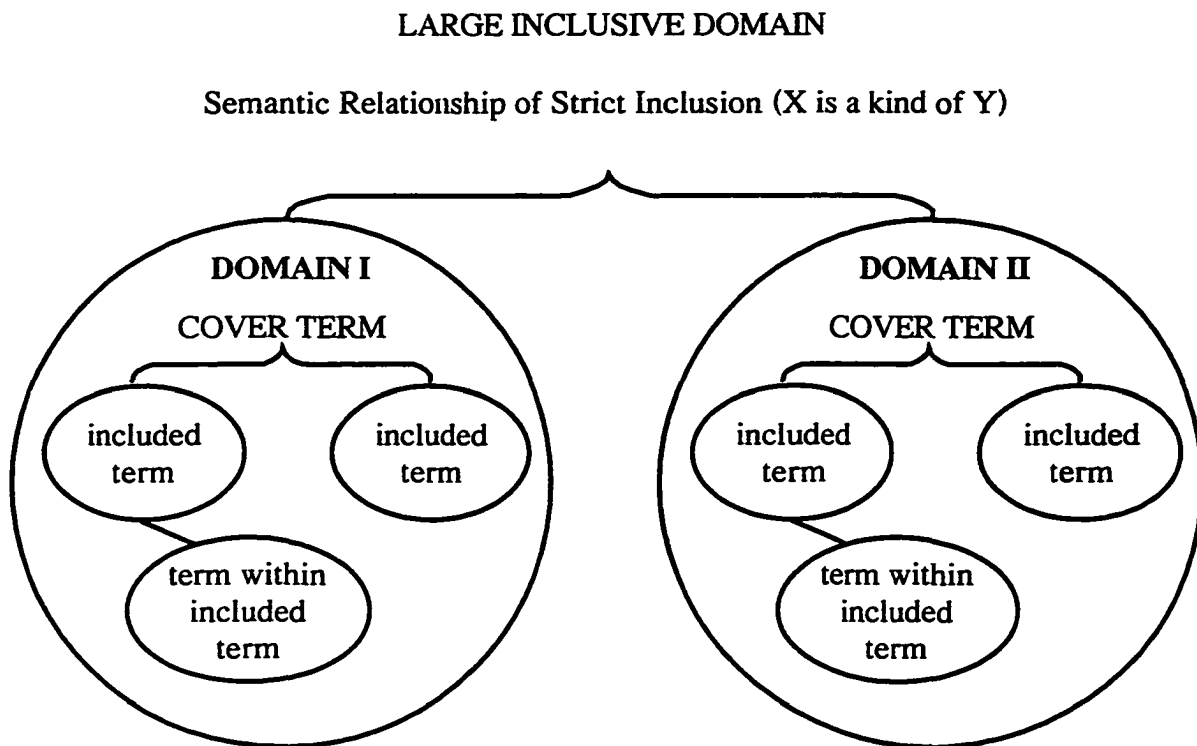
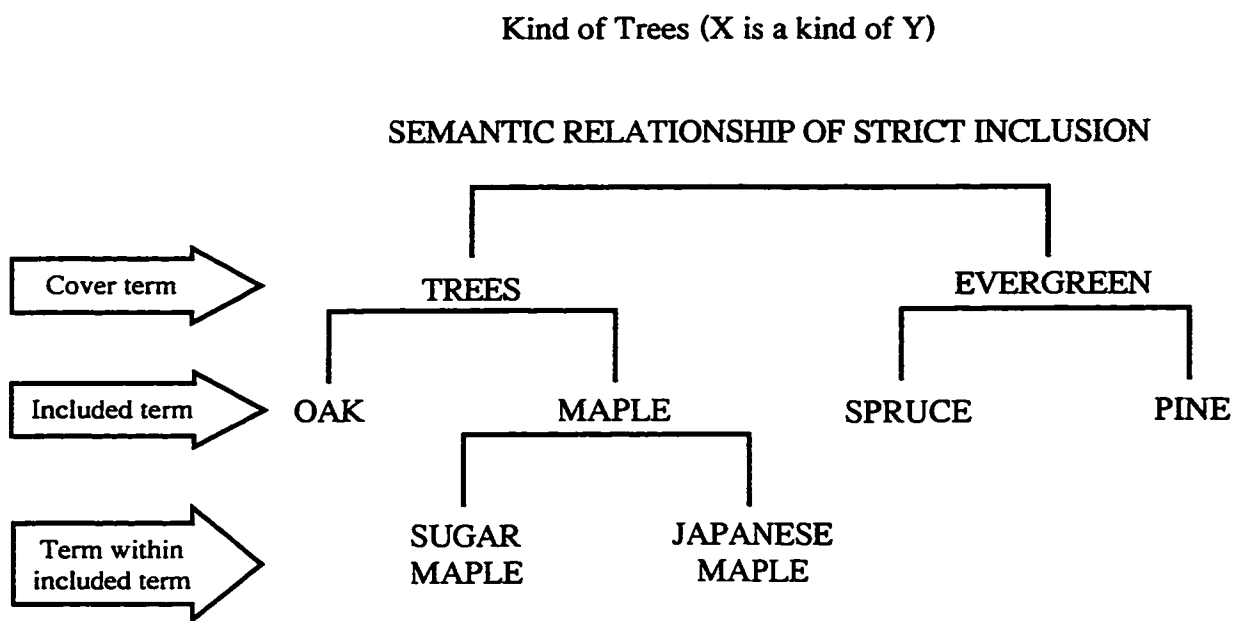
Included Terms	Semantic Relationship	Cover Term
<ul style="list-style-type: none"> - It changes everything - I remember looking at the hospital and when I saw "Cancer" (in the name), you know, it got to me - I felt so depressed, I can hardly explain it - to do those tests. I had to spend the whole day. I remember I cried: it was very difficult. - Just hearing the word "cancer" - If there are others in the house and they don't know anything about it, it's difficult. 		Stigma
Contrast Question: What are some of the changes?		
Included Terms	Semantic Relationship	Cover Term
<ul style="list-style-type: none"> - since they took off my breast - just hearing the word "cancer" - going to bed at night, it is the last thing on my mind, and - waking up in the morning, it is the first thing on my mind - not working - not having my breast - like when you see yourself and you see you have just one breast - it's difficult to walk around in your nightie - it's difficult to go to the beach with my swimming suit - I don't use red meat all that much 		My whole life changed

Figure 3. Making a Taxonomic Analysis*.



* adapted from Spradley (1979)

Figure 4. Taxonomic Analysis Example*.



* adapted from Spradley (1979)

Figure 5. Taxonomic Analysis of Loss. Informant # 1 (Yolande).

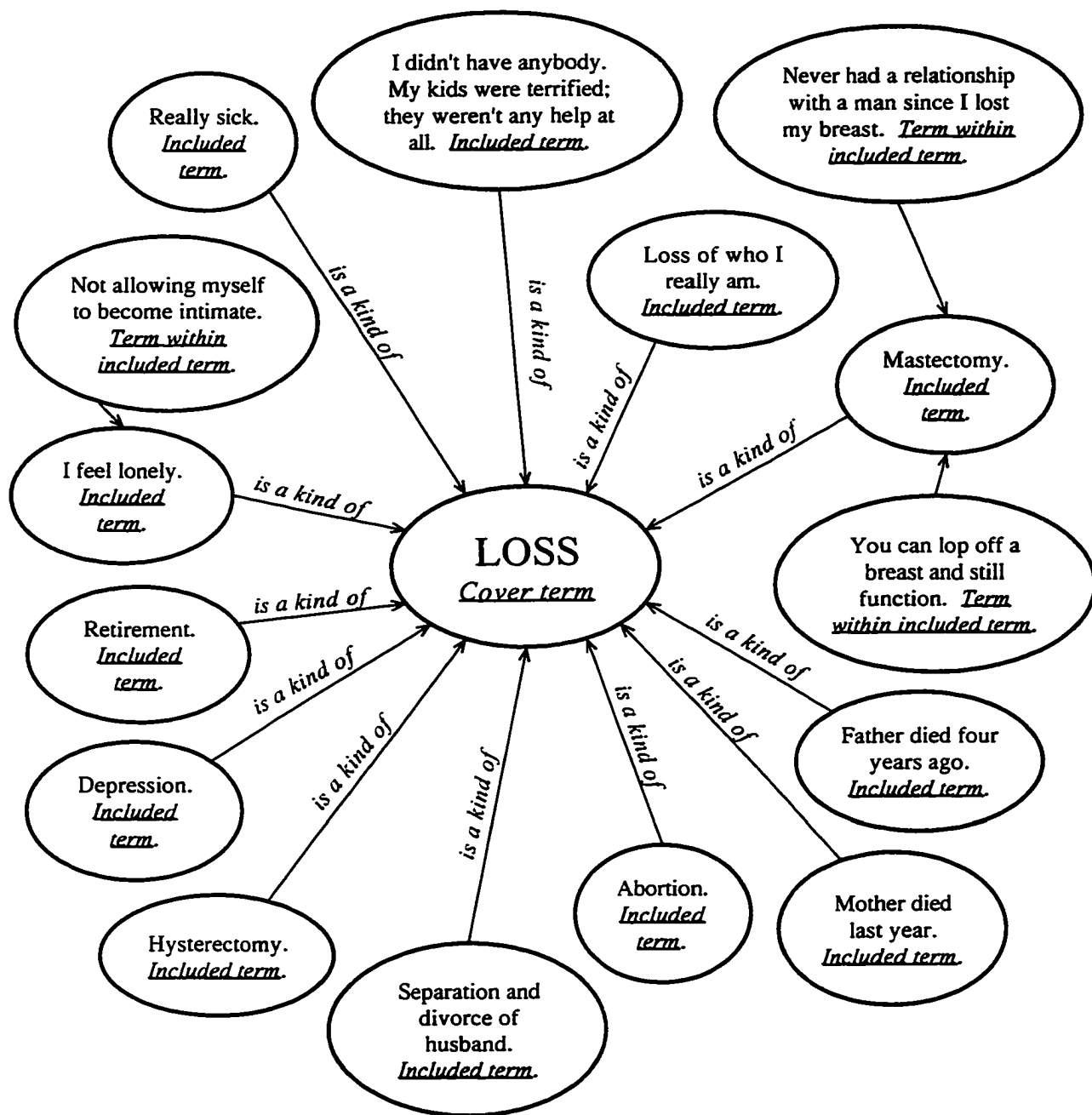
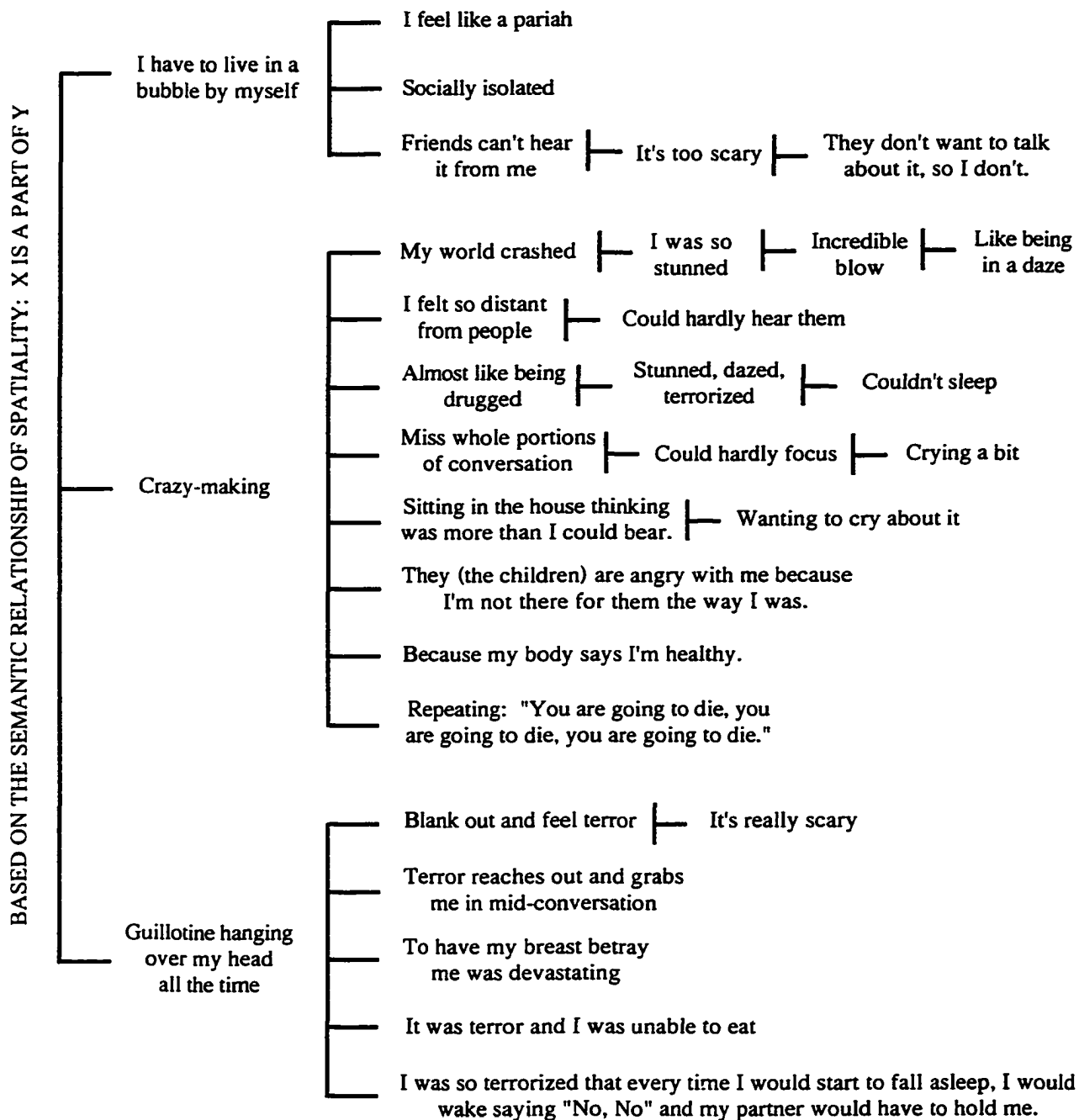
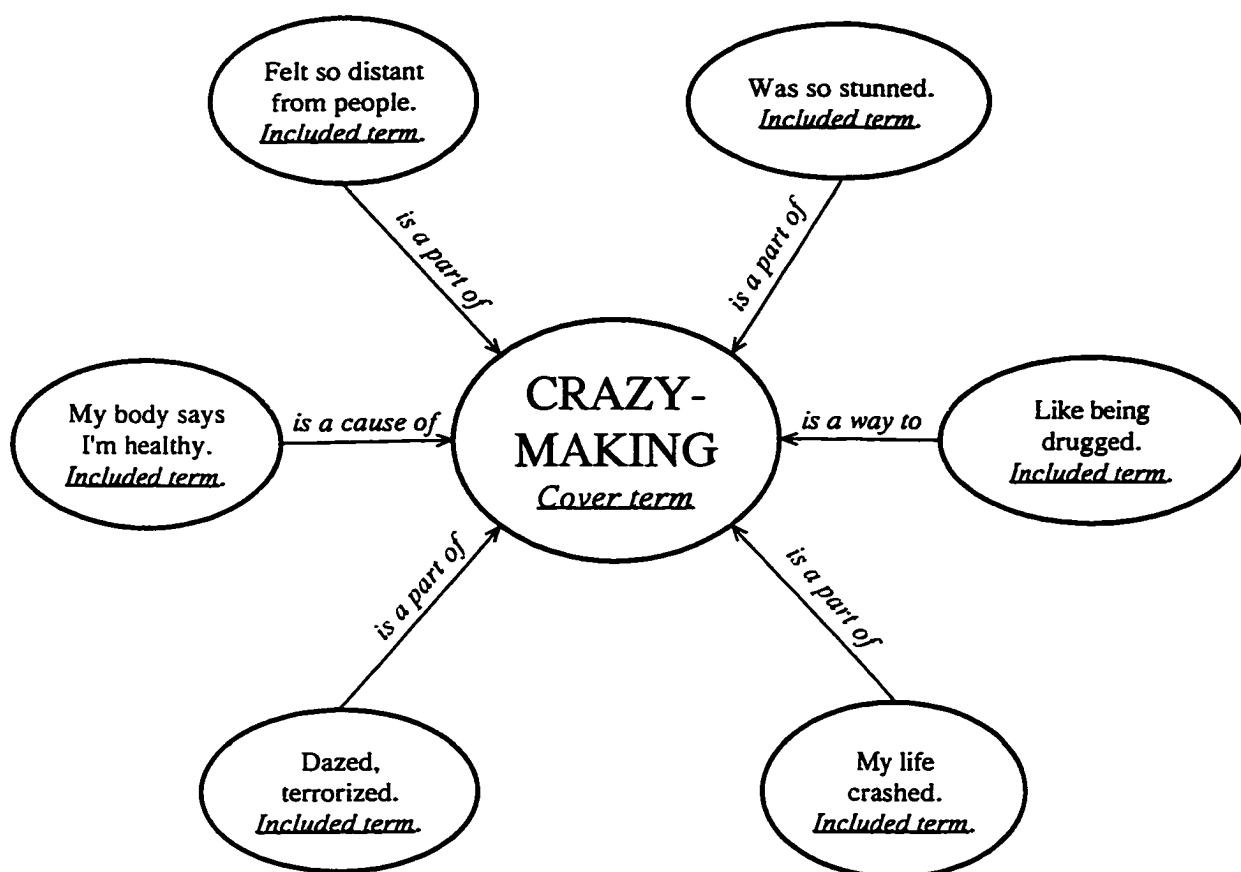


Figure 6. Taxonomy of a Part of Feeling My Whole World Had Crashed.
Informant # 2 (Denise Forest).



* adapted from Spradley (1979)

Figure 7. Step in Componential Analysis*: Some Attributes & Semantic Relationships of Crazy-Making. Informant # 2 (Denise Forest).



* adapted from Spradley (1979)

Figure 8. Paradigm Worksheet*.

Example of Information for a Componential Analysis of Reasons for Experiencing Fear. Informant #3 (Jane).

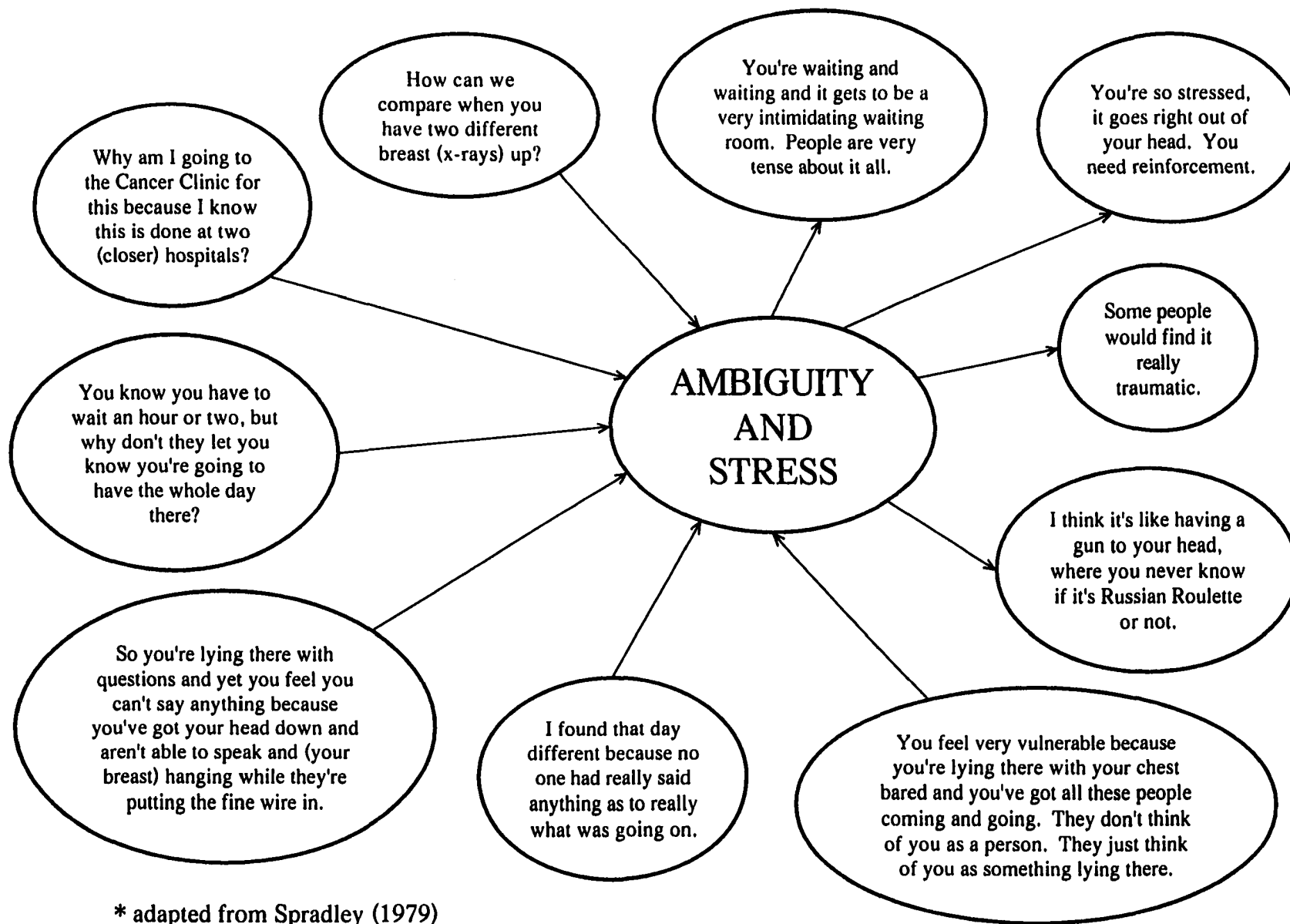
DOMAINS	DIMENSIONS OF CONTRAST (YES/NO)								
	Rigid with fear	Bad feeling right away	Awake most of night worrying	Horrible sinking feeling	Absolute numbing terror	Awful feeling it wasn't good	Terror sweeps over like a wave	Utterly depressed to the point of being terrified	Feeling of absolute numbing terror
Haven't been able to eat	yes	yes	yes	yes	yes	yes	yes	yes	yes
Don't think I can handle anything else	yes	yes	yes	yes	yes	yes	yes	yes	yes
It was bigger than she thought	yes	yes	yes	yes	yes	yes	yes	yes	yes
I've done it to myself	yes	yes	yes	yes	yes	yes	yes	yes	yes
This isn't healthy	no	yes	yes	yes	yes	yes	yes	yes	yes
Arrangements as if it were bad	no	yes	yes	yes	yes	yes	yes	yes	yes

Possible Themes:

- Fear
- Powerlessness
- Lack of control
- Self-blame
- obsession

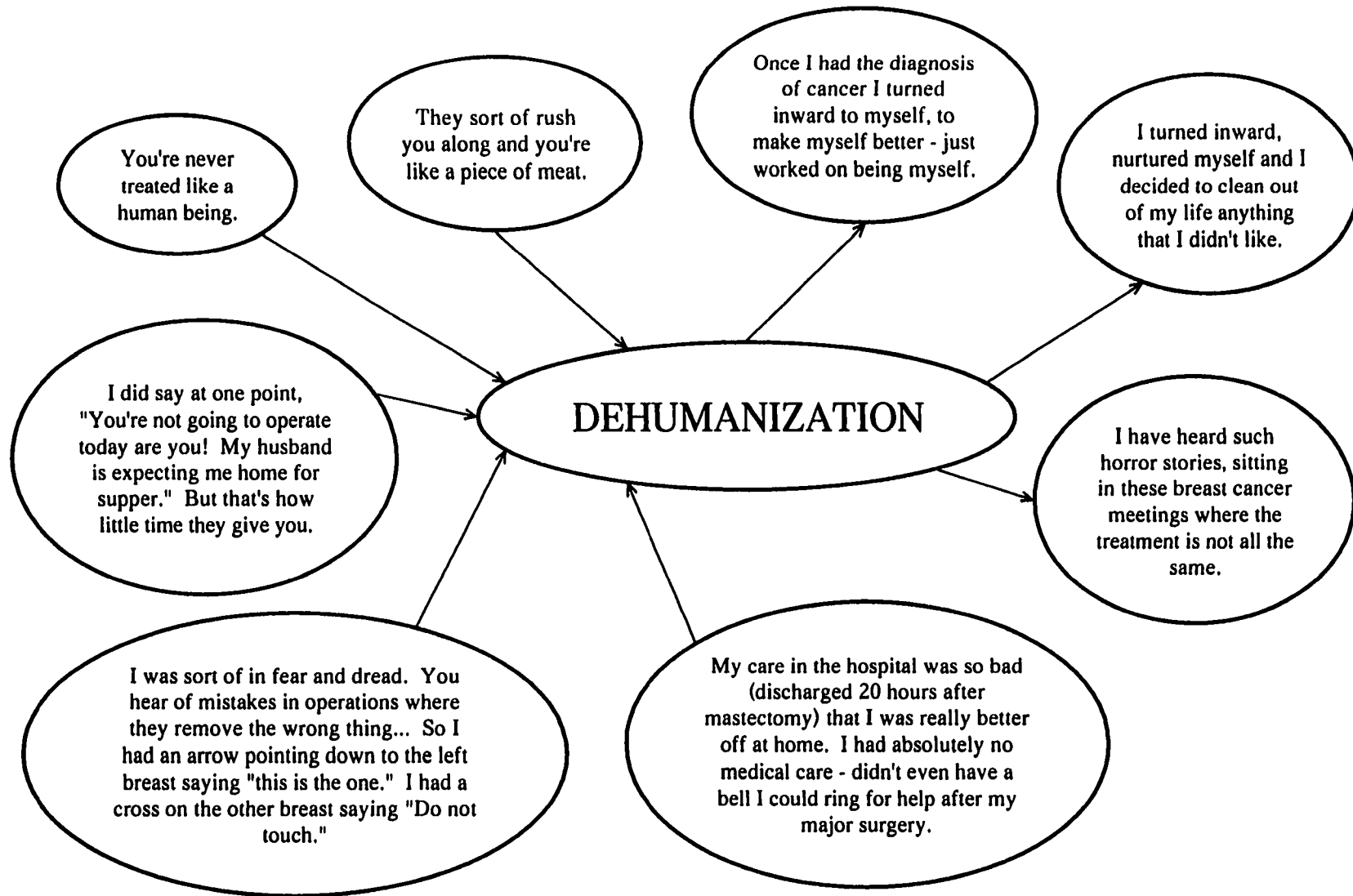
* adapted from Spradley (1979)

Figure 9. Discovering Cultural Themes*: Ambiguity and Stress. Informant # 6 (Anne Marie).



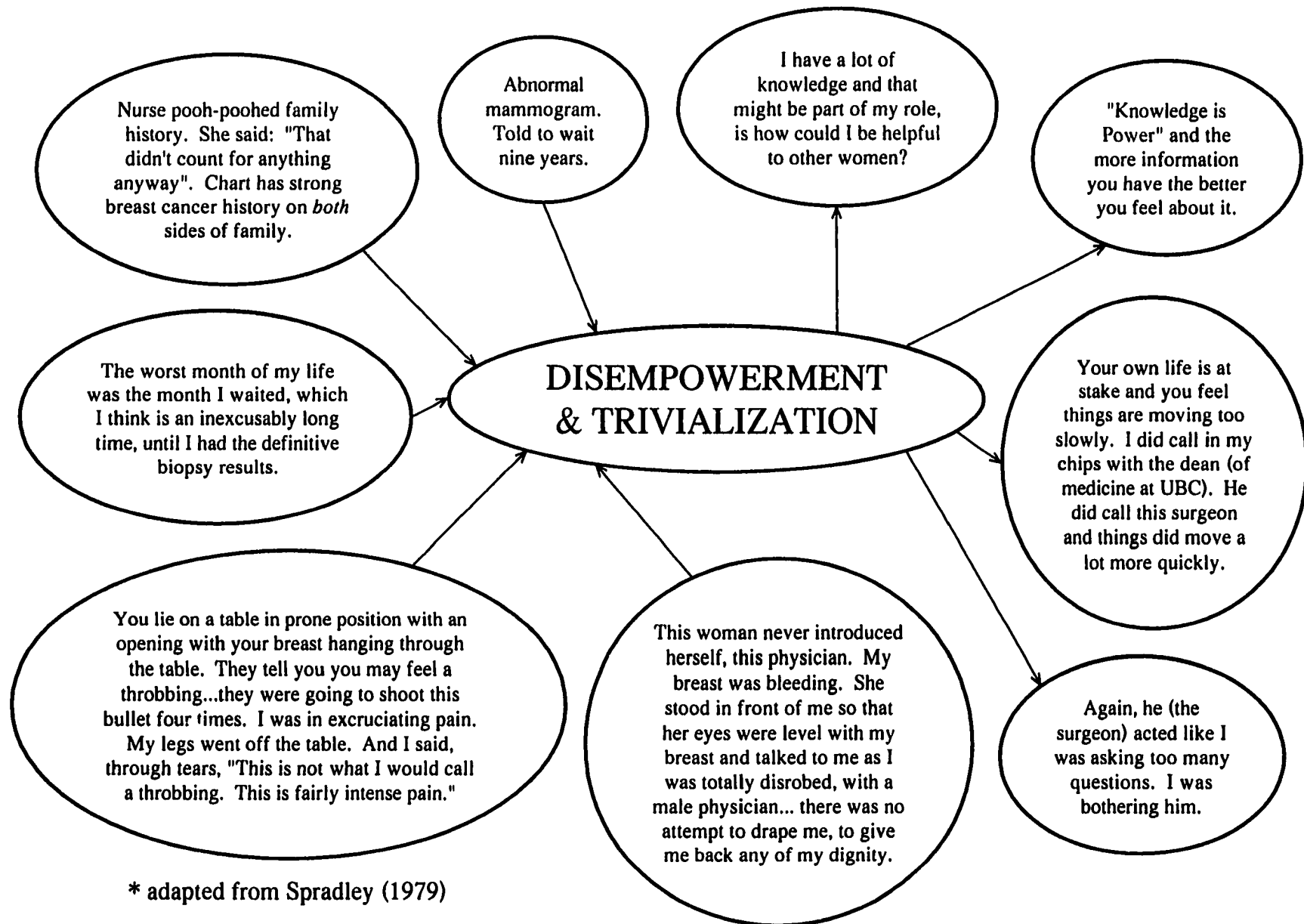
* adapted from Spradley (1979)

Figure 10. Discovering Cultural Themes*: Dehumanization. Informant # 7 (Sharon).



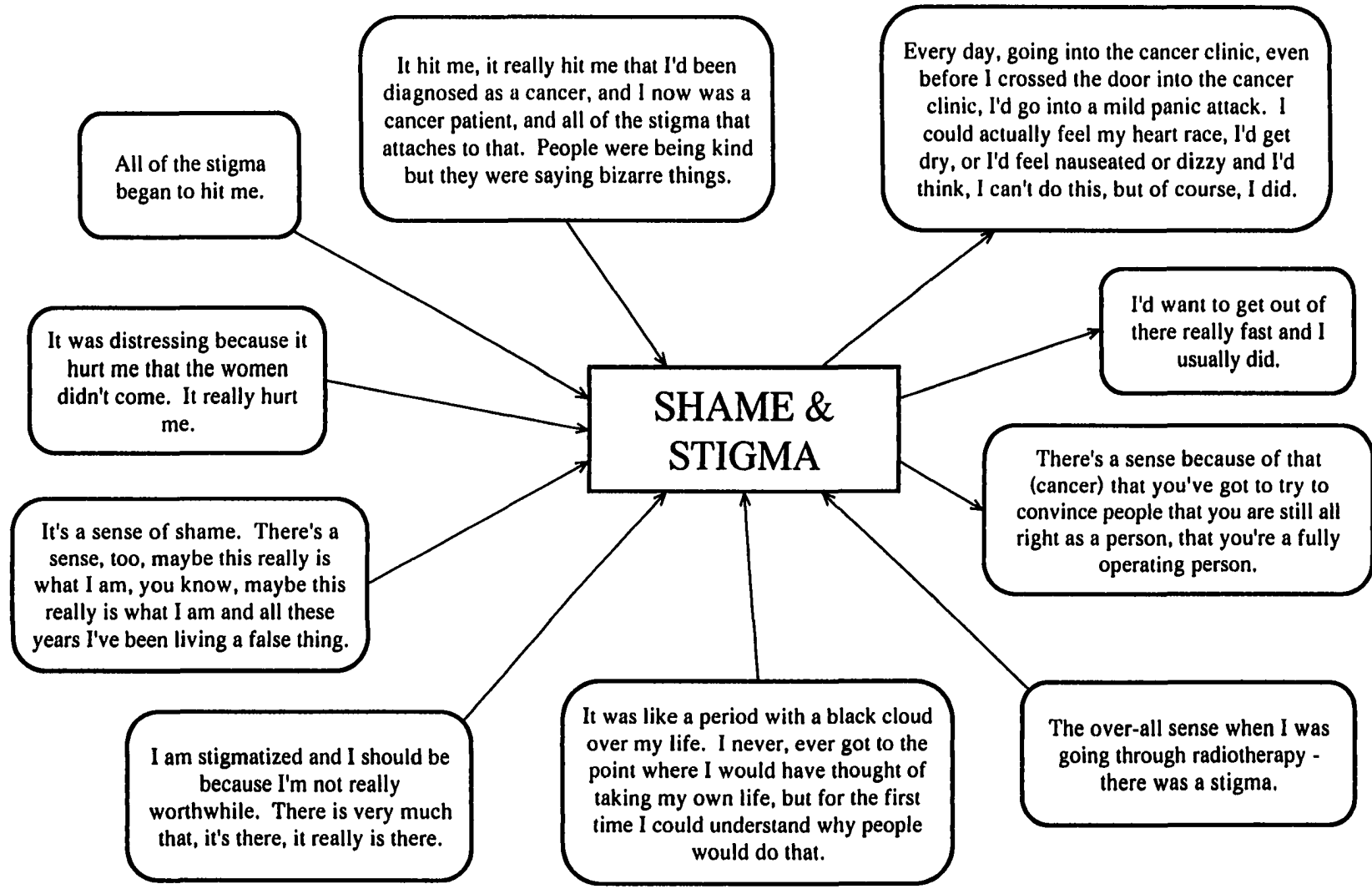
* adapted from Spradley (1979)

Figure 11. Discovering Cultural Themes*: Disempowerment and Trivialization. Informant # 8 (Susan Harris).



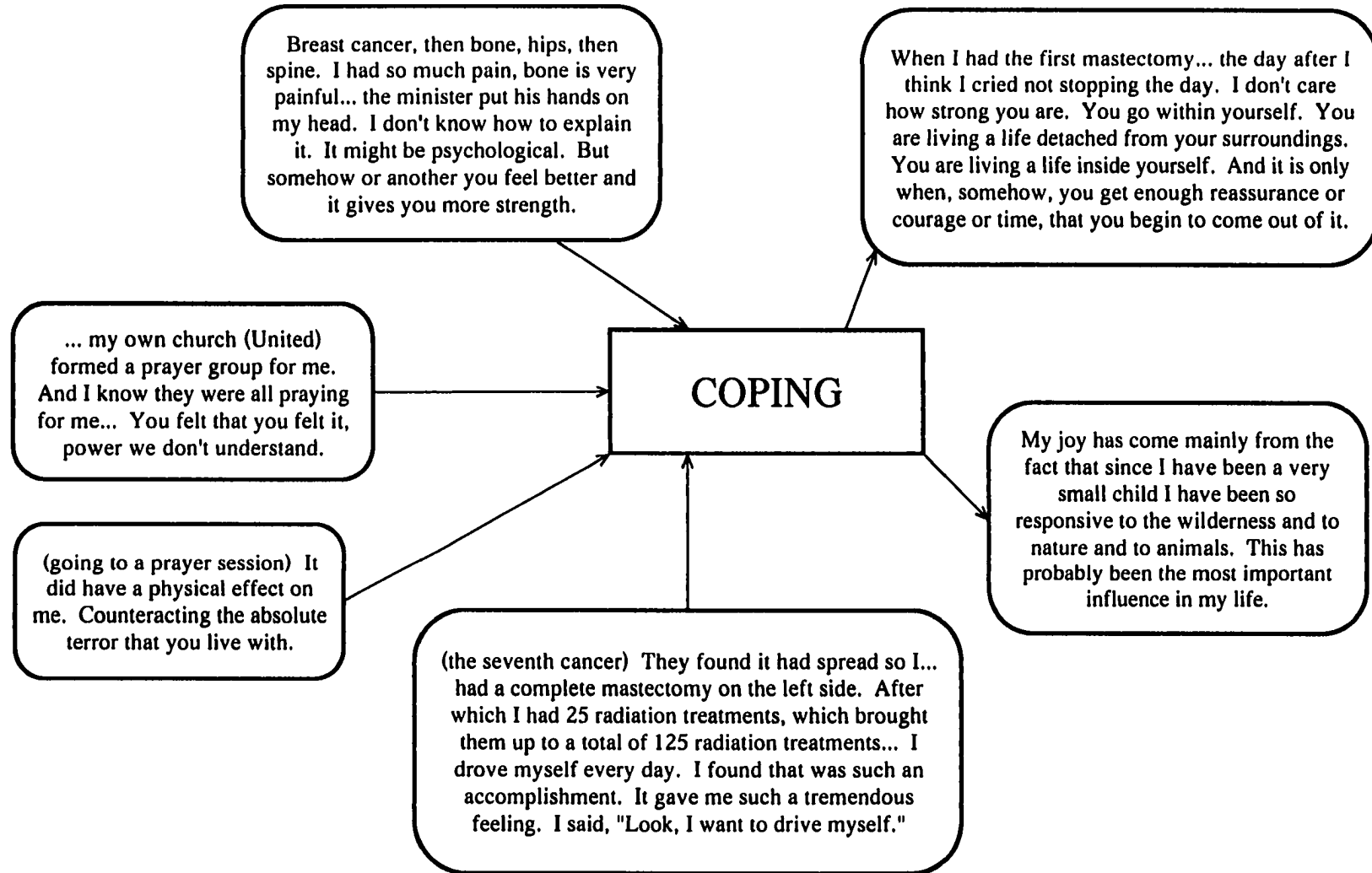
* adapted from Spradley (1979)

Figure 12. Discovering Cultural Themes*: Shame and Stigma. Informant # 9 (Carol).



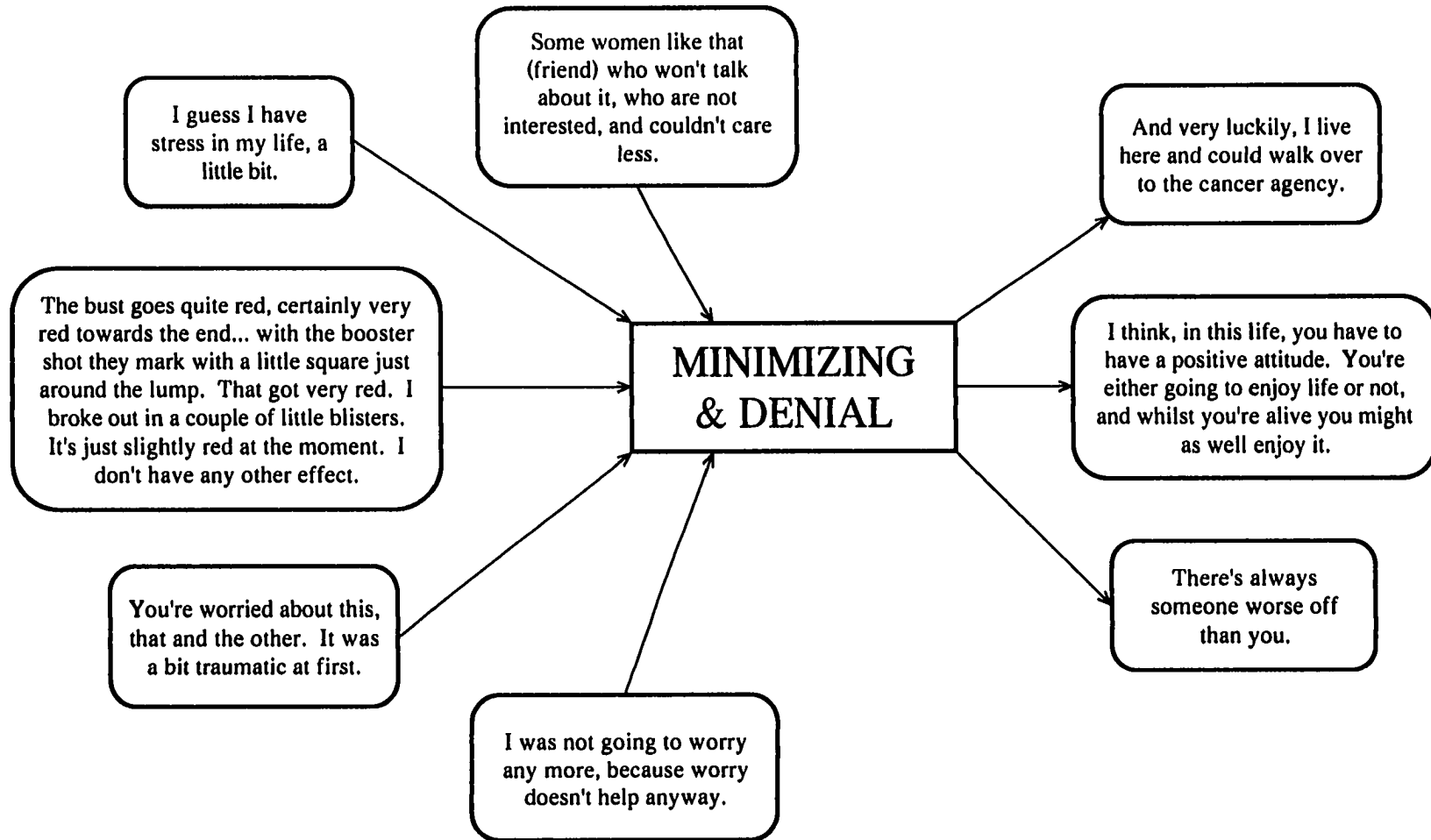
* adapted from Spradley (1979)

Figure 13. Discovering Cultural Themes*: Coping. Informant # 10 (Vera).



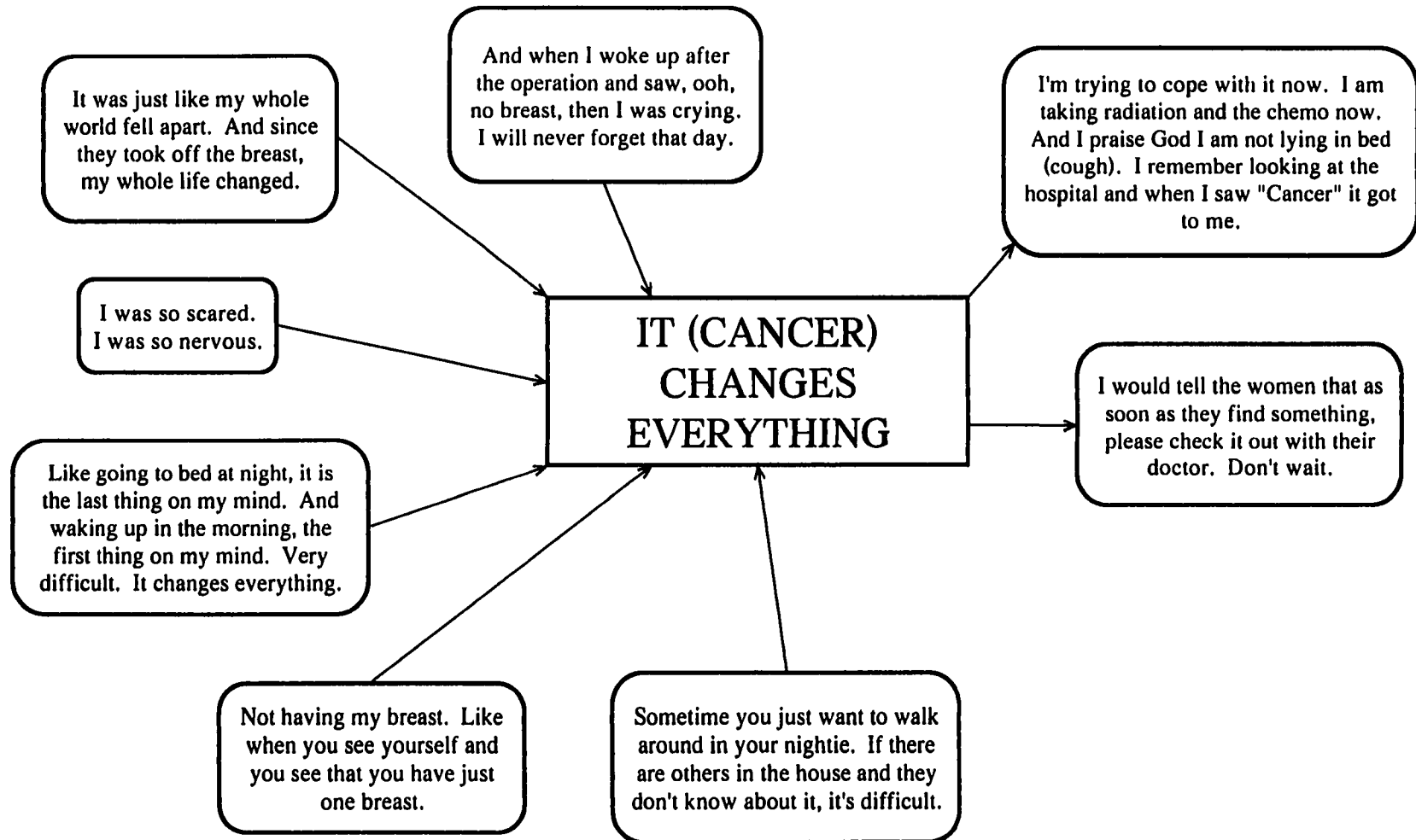
* adapted from Spradley (1979)

Figure 14. Discovering Cultural Themes*: Minimizing and Denial. Informant # 11 (Donna).



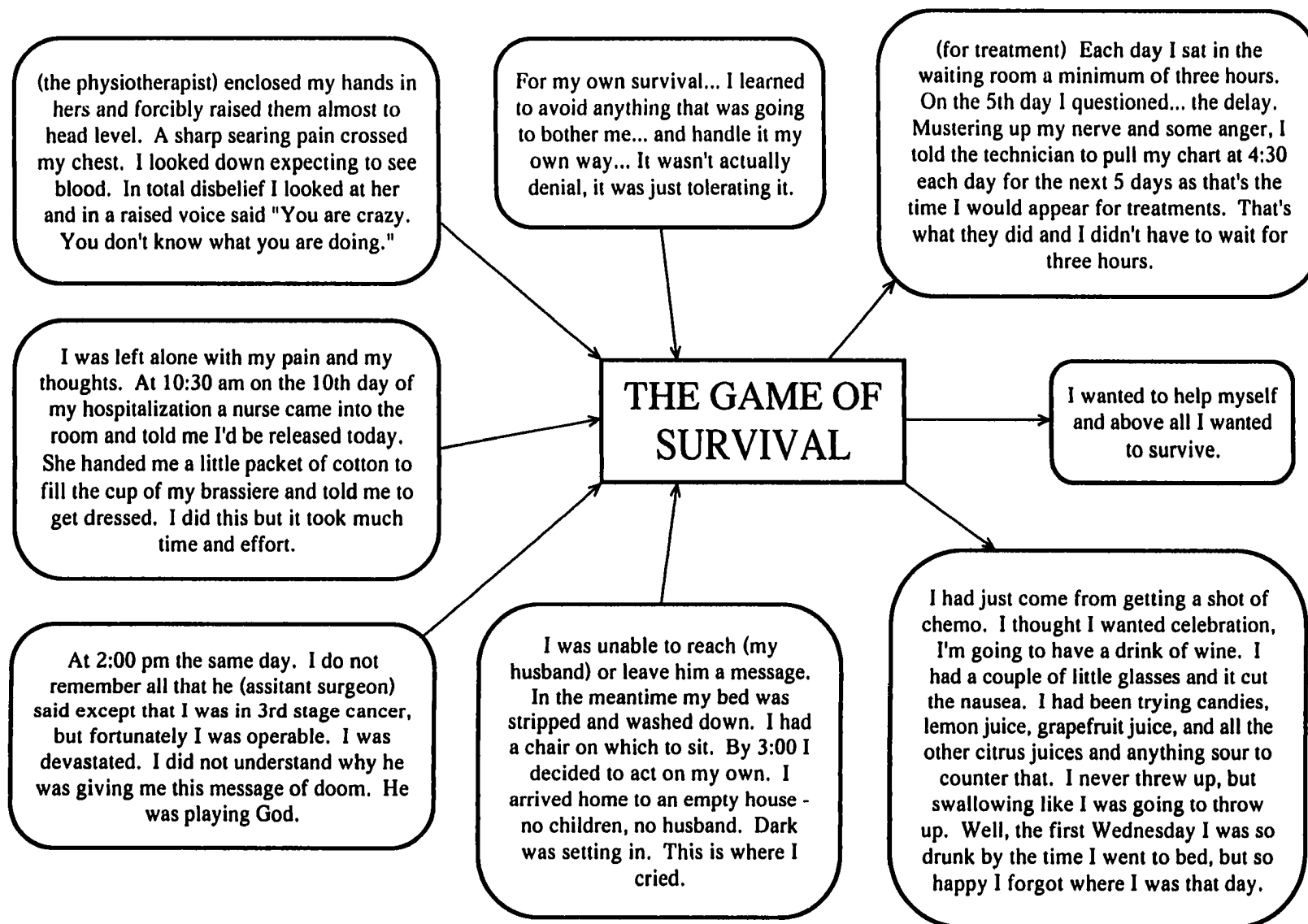
* adapted from Spradley (1979)

Figure 15. Discovering Cultural Themes*: It (Cancer) Changes Everything. Informant # 5 (Laura).



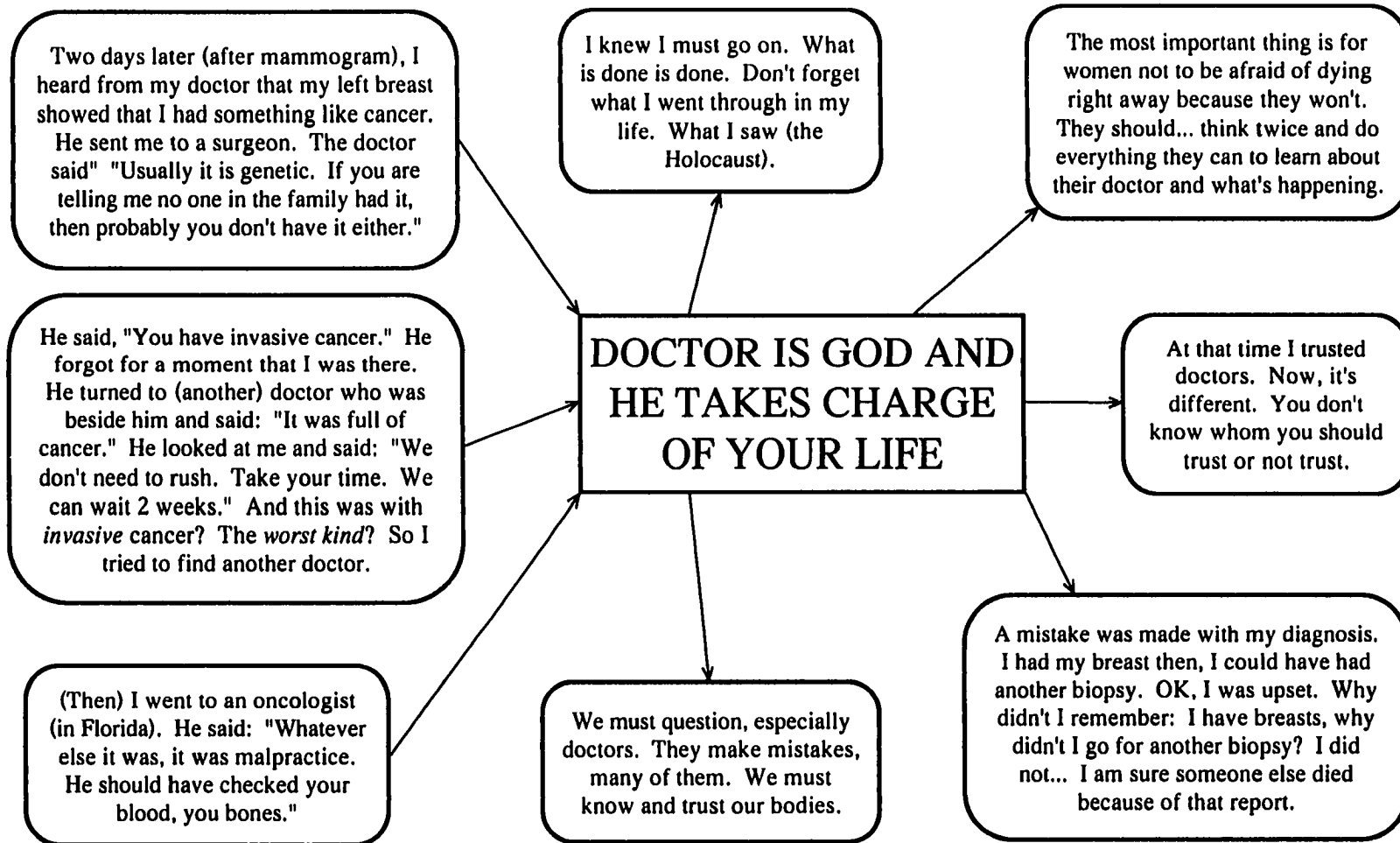
* adapted from Spradley (1979)

Figure 16. Discovering Cultural Themes*: The Game of Survival. Informant # 12 (Margaret).



* adapted from Spradley (1979)

Figure 17. Discovering Cultural Themes*: Doctor is God and He Takes Charge of Your Life. Informant # 13 (Rose).



* adapted from Spradley (1979)

Figure 18

Discovering Cultural Themes: Metaphors/Imagery of Twelve Informants

Yolande

- I think I denied a lot about the trauma of having a breast removed.
- I have never had a relationship with a man since I lost my breast.
- I protected myself . . . not allowing myself to be intimate.
- I put up a wall.
- My kids were just terrified over it . . . They weren't any help at all.
- What I was doing was, I was trying to hold them together.
- I felt really alone.
- It was this whole thing about being brave and strong, and that's denial.
- Always trying to be perfect, and not to let (anyone) down.
- Being stoical.
- So it's "just a breast . . . ha, ha, ha." Well, it's more than "ha, ha, ha!"
- My children were so frightened that they just really didn't know what to do about Mother, who had always been so strong.
- It was so important to me to be strong for them.
- There's a cost when I had my breast removed, and then, BOOM!
- So although you think you are coping, you really aren't because then you go "pfffft!"
- It is not just a physical thing, it is a highly emotional situation . . . it is part of your sexuality
- it is part of your sexuality--so there's a whole bunch of things around that.
- I don't think you are ever free of fear.
- You can't separate this from the rest of your body, you know.
- being whatever I am supposed to be.
- the death of something you love, or someone you love--the same feeling.
- it was like somebody phoning you to tell you that somebody had died.
- I remember when my father died--my sister phoned--it was the same feeling, like someone had kicked me.
- that was the same feeling, the loss of something or somebody you love
- the loss of something dear to you. Your breast!
- it's just a stacking of losses
- well, it's just another loss for me, you know.
- I was raised not to make a fuss.
- I've tried to trivialize it.
- I'm starting to realize that I made the mistake of trivializing it.
- You can lop off a breast and you can still function.
- I've paid a price, a big one.
- I just kind of shut the door on it.
- "Oh, well, you get on with your life."
- I won't allow myself to trivialize it any more.
- Cancer should not be taken lightly.
- We need to embrace each other emotionally and physically when something like this happens.
- I think it's the old thing about educating people.
- loss of who I really am.
- events . . . have flattened me to the point of . . .
- I almost feel like a flattened car, the kind of cars that are squeezed down, so that they no longer look like a car.
- I'm going to do something about this bloody anxiety and depression that keeps following me around like a black cloud.
- We have been taught not to make a big issue of it, that it's just a breast and you can always have breast reconstruction. Well, bullshit, it isn't.

- there should be a buddy system
- aren't you going to have reconstruction?
- sex--I don't have as much urge and that bothers me

Discovering Cultural Themes:

Metaphors/Imagery of Twelve Informants (cont'd)

Elaine Zyri

- like I'm living in grace. . . I certainly don't get bent of shape anymore
- D. got bent out of shape with me this summer and beat me up
- it's almost like I'm stupid
- I sort of picked up the pieces
- my world fell apart
- the path of having breast cancer
- nobody thinks I have any value whatever
- I'm a rascal at heart
- I will jump ship when I'm ready, I won't be pushed out
- at home, we're not real
- if you don't want me to rip all my clothes off and take this place apart, you'd better get me the manager right now
- I will begin to strip my clothes
- it's entirely up to you whether you want to have a nude one-tit woman running around here or not
- I just got spunky lately
- that's what I meant by being a rascal. I am a rascal.
- it's very sad to lose your boob
- it's better to be the master of your own destiny, to read over your chart, get a second opinion
- this is not going in and getting a big toenail taken off. No.
- once your boob is gone, that's it. You don't grow it back
- I'm a mouthpiece

- Dad, if you were the pilot of a 747, would you like a passenger coming up and telling you how to do it, all day, every day? He said, "No." And I said, "Precisely."
- more master of my destiny, more interest in controlling my life
- not being a people pleaser
- be a child again, get back into your creativity
- if somebody was living in a cave--that was very sad and lonely and unhappy
- Now, since I've had the cancer, I've turned in to a beautiful older woman who wanders around in a beautiful field
- I've been transformed
- I'm more of my own person. I'm Elaine and I can't have that taken away from me

Denise Forest

- the grieving stuff--haven't entirely laid it to rest
- my whole world had crashed in
- my life has crashed, I'm stunned
- it (diagnosis) was such an incredible blow
- to have my breast betray me was just devastating
- it was like being drugged
- working was a life line
- reach out and grab me in the middle of a conversation
- I would blank out and feel the terror of it
- isolated myself
- burden of support has fallen on her
- feel like a pariah
- have to live in a bubble by myself
- it's crazy-making
- feel like I have a guillotine hanging over my head
- I don't feel any time bomb in there all the time
- it's already the worst thing

Discovering Cultural Themes:
Metaphors/Imagery of Twelve Informants (cont'd)

Susan Harris

- They pooh-poohed the family history.
- had another scare (mammogram)
- my first inkling something was wrong (the technologist did not respond)
- the unknown is a whole lot worse than the known--that is the biggest picture
- first I was playing with 80/20 odds, then 50/50 odds
- the worst month, worse than anything else I went through, that not knowing
- the seeming incommunication between physicians as far as what was happening and the next step
- each specialist was superb, but the right hand never knew what the left hand was doing
- (the hospital)--no more client-centred than the man in the moon
- strikes terror in your heart
- most barbaric procedure--core biopsy
- shoot in like a little guillotine that pulls out a plug of tissue
- I'm a pretty tough old bird--and it was extremely painful
- odds--now 75% that it is (cancer)
- knowledge is power. The more information you have, the better you feel about it
- I did call in my cards with the Dean of the Faculty of Medicine (at UBC)
- I don't believe in rocking the boat, but when your own health is at stake--
- I did call in my chips with the Dean
- how sad that even with the Dean in my back pocket I still have this wait for radiation treatment
- surgeon shared his plan based on size of the tumour and that is the benchmark
- told I would have chemo, to falling apart

- I would zap this thing to Kingdom Come
- half of me had risen to the occasion and wanted to do everything possible
- then I set forth and read everything possible
- everything I read was equivocal, in a grey zone
- had a 1-in-250 chance of dying of the chemo
- increase my cold feet
- frosting on the cake that I was not a candidate for this (chemo)
- laid out the whole radiation plan
- I'm on the outer edge of waiting already, even with going to Bellingham (USA)
- it kinds of makes you angry when you have done those things right and you still get stuck with this
- somebody in my family said something (about stress) and I barked at them
- I'm not willing to wait. But it is going to mess up my life in the interim
- 15 volunteers (to help me drive to the USA). But I can't plug them in until I know when all this starts
- one of the hardest things--the length of not knowing
- it has made me smell the roses a bit, slow down
- being the perfect professional and doing all the right trip and plugging
- "Oh, I didn't have to do the chemo, so I'm not being punished, so I better plug back in."
- the roller coaster. There have been some incredible lows, particularly the month of not knowing
- the chemotherapy roller coaster of: "no, you're not going to have it," "yes, you're going to have it," "no, you're not," "yes, you are."
- the incredible outpouring of love is the highs of the roller coaster this kind of hits you
- (nothing in the literature about smoking) I thought, this is bizarre. So I thought, "Well, that's what I've done wrong. I haven't smoked enough."
- my armpit looks like hell. Nobody ever loved my armpit

- my left breast looks a little perkier than my right breast
- it looks about 26 and my right breast still looks 46.

Discovering Cultural Themes:

Metaphors/Imagery of Twelve Informants (cont'd)

Sharon

- cancer--the most stressful thing I was hit with
- life is terminal
- they sort of rush you along and you're like a piece of meat
- you're never treated like a human being
- my breasts aren't important to me, I'd rather have my health
- a funny looking breast is going to be worse to look at than no breast at all
- Susan Love's Breast Book--I really call it my bible now--we both read it
- I was sort of in fear and dread, you hear of mistakes in operations where they remove the wrong things
- my care in hospital was so bad that I was really better off at home than staying in the hospital
- life goes on
- arm, red and swollen, called the doctor. He looked at it and said, "It looks like a mosquito bite."
- the nurse came and said, "You're got lymph edema"
- the news about the cancer--little bit of shock that I had so many lymph node involved. Ten out of 20 nodes had cancer in them
- I go there and I speak out and somehow by saying something and getting it off your chest, somehow it doesn't seem as important anymore or as bothersome
- You've gotten rid of it
- it came out of left field, in my mind, and I was more surprised
- I turned inward
- I decided to clean out of my life anything that I didn't like
- I never feel at a loss

- I just used Pac Man for going around gobbling up the cancer cells when I was doing visualization
- then, I'd use rubbing alcohol and take my brain out and clean it with rubbing alcohol, then with my luck, I'd die of alcohol poisoning (her laughter)

Anne Marie

- they lobbed them (breasts) off, and then they left them (women)
- I look at my cancer and I think, oh, God, that's so mild
- mine is just mini, mini in the big gamut of what it could be
- mine is just a little weeny bit in the gamut of what could be
- you've got your mind already set, that you probably have cancer (the procedure) was one of the more traumatic things for me
- you just feel like you're being done
- they don't think of you as a person. They just think of you as something lying there
- I dissolved . . .
- I'm finished
- a breast doesn't mean much to surgery people, because it's not like you're lying there with abdominal or some major heart thing or something that is life and death
- this is just an appendage
- I can see a big trauma happening
- it's very traumatic for women to be diagnosed
- you always think of cancer as being dramatic
- this breast is a big, big issue
- it appears to be a systemic disorder, rather than just these appendages--part of the whole body
- you do have little episodes--I did break open a bit and was bleeding
- I can get my thing taken off, my breast.
- that was a bit of a trauma (radiation)
- some people would find it really traumatic
- compared to the old mammogram, they crush you before they even come around the corner
- there is no comparison

Discovering Cultural Themes:
Metaphors/Image of Twelve Informants (cont'd)

Carol

- (after all the tests) I wasn't in the mood to fight
- just before Christmas, I started radiation, and that was when it hit me
- it hit me with a wall
- it hit me, the reality hit me that I'd been diagnosed with cancer
- all of the stigma began to hit me
- the cancer personality
- sense of shame
- I am stigmatized and I should be because I'm not really worthwhile
- convince people . . . that you're a fully operating person
- a black cloud over my life
- feelings hit me frequently
- guilty--lolly-gagging around
- push, push, push, and bring in whomever you have to help you

Jane

- this hole in me, emptiness in me
- felt flattened, kind of numb
- disintegrate
- left hanging
- get on the tread mill
- like a betrayal, passed that hurdle
- not past hurdle; it tipped over, you're on the ground
- chemo as safety net
- chemo was my gardener, going in and rooting out bad stuff
- terror just sweeps over you , like a wave

- you feel consumed by it

Vera

- every human being, when they feel threatened, turns to something more powerful, larger, more encompassing
- opening self up to healing
- blind and walking toward a cliff and I don't know how far it is and when I am going to come to it
- live with terror
- doesn't matter whether you are rich or poor, cultured or simple, king or scavengers--roles on stage of life
- curl up in a little ball and not want to see people and do things you go within yourself. . . living a life within yourself

Rose

- the diagnosis. . . hit me like a rock
- I lost it
- arm and shoulder--like a block of wood
- doctors here are only interested in money. Just like any business man
- don't lose your head
- the doctor is your god, and he takes charge of your life

Laura

- we have to work on it right away
- it was huge, it was spreading so fast
- my whole world fell apart
- my whole life changed
- it got to me
- receptionist--just the look on her face--cancer

Discovering Cultural Themes:
Metaphors/Imagery of Twelve Informants (cont'd)

Margaret

- the first biopsy--it really destroyed me
- handle it in my own way
- Reach for Recovery women--almost like performers
- "45-year-old mastectomy"
- experiencing total fear
- state of shock
- devastated--message of doom
- tears . . . began to stream down my face
- release of all the pent-up emotions from the first announcement of cancer, borne in silence
- one of turning points of my life at the time--resume work

- it was a long road, but I got here on my own
- cancer--it's an automatic death sentence
- it's a pronouncement of death
- I don't want to be an experiment
- it is such a horrible, painful, bloody damn death
- you have to go to the bottom of the stairs before you can climb up
- when you have cancer, that's where you end up, right at the bottom
- it's one step at a time
- the game of survival
- you've had a good life, now this is what tested you
- stand up for yourself, be yourself--learning process
- found out that doctors weren't God

Figure 19. Major Recurrent Themes - Universal Cultural Themes: Adaptation to Ambiguity (Stress).

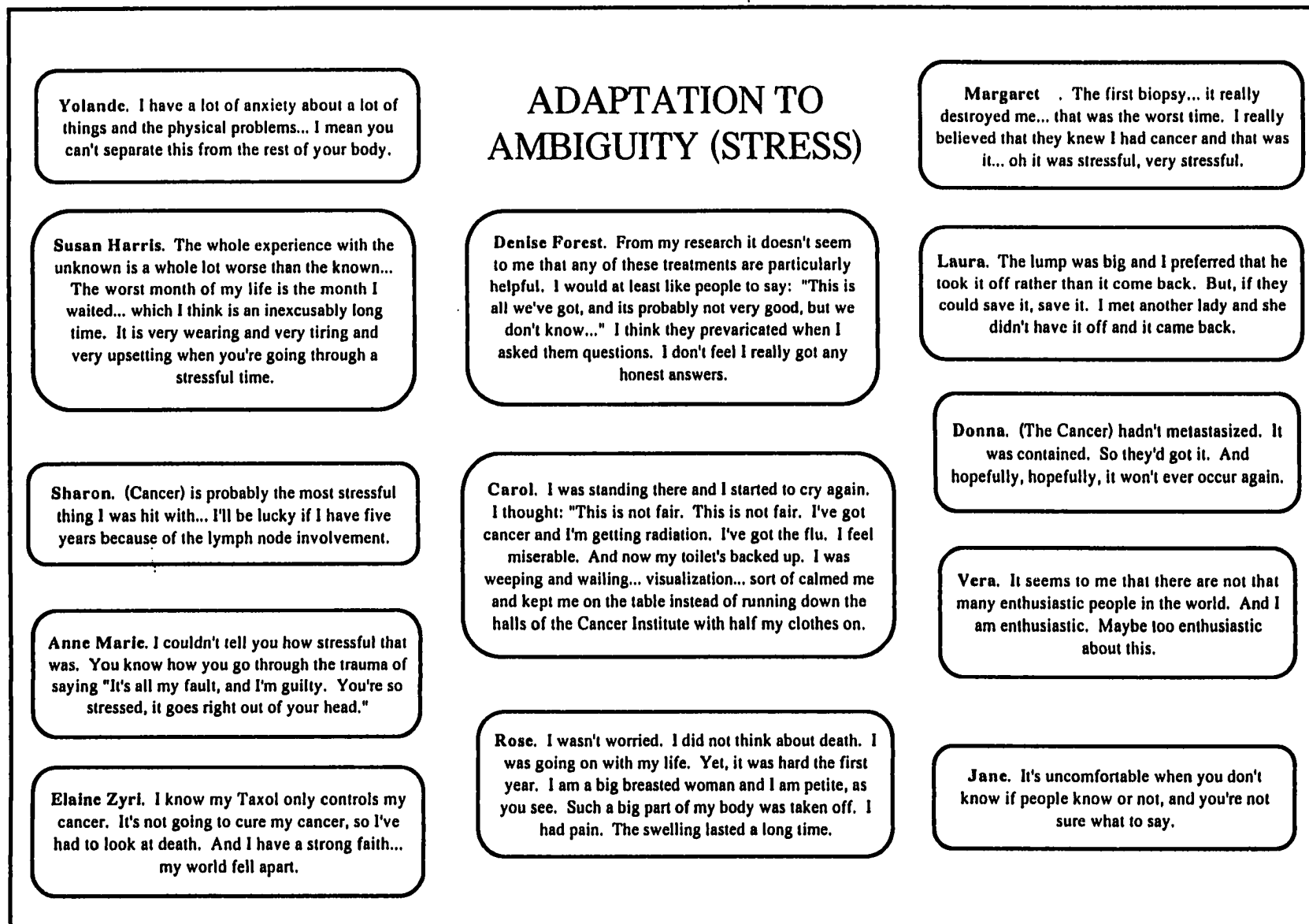


Figure 20. Recurrent Themes - Universal Cultural Themes: Sadness and Anger.

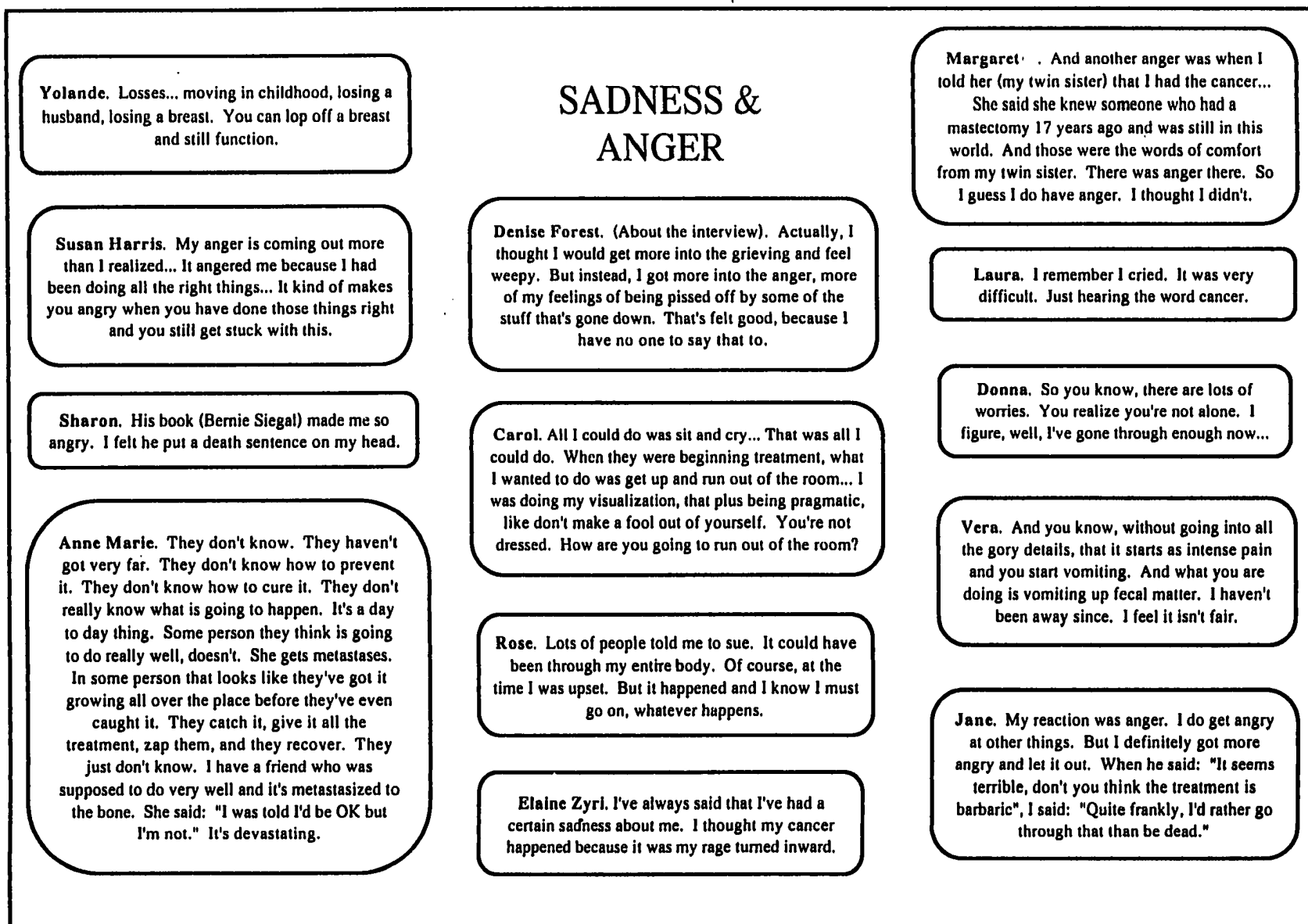


Figure 21. Recurrent Themes - Universal Cultural Themes: Fear and Terror.

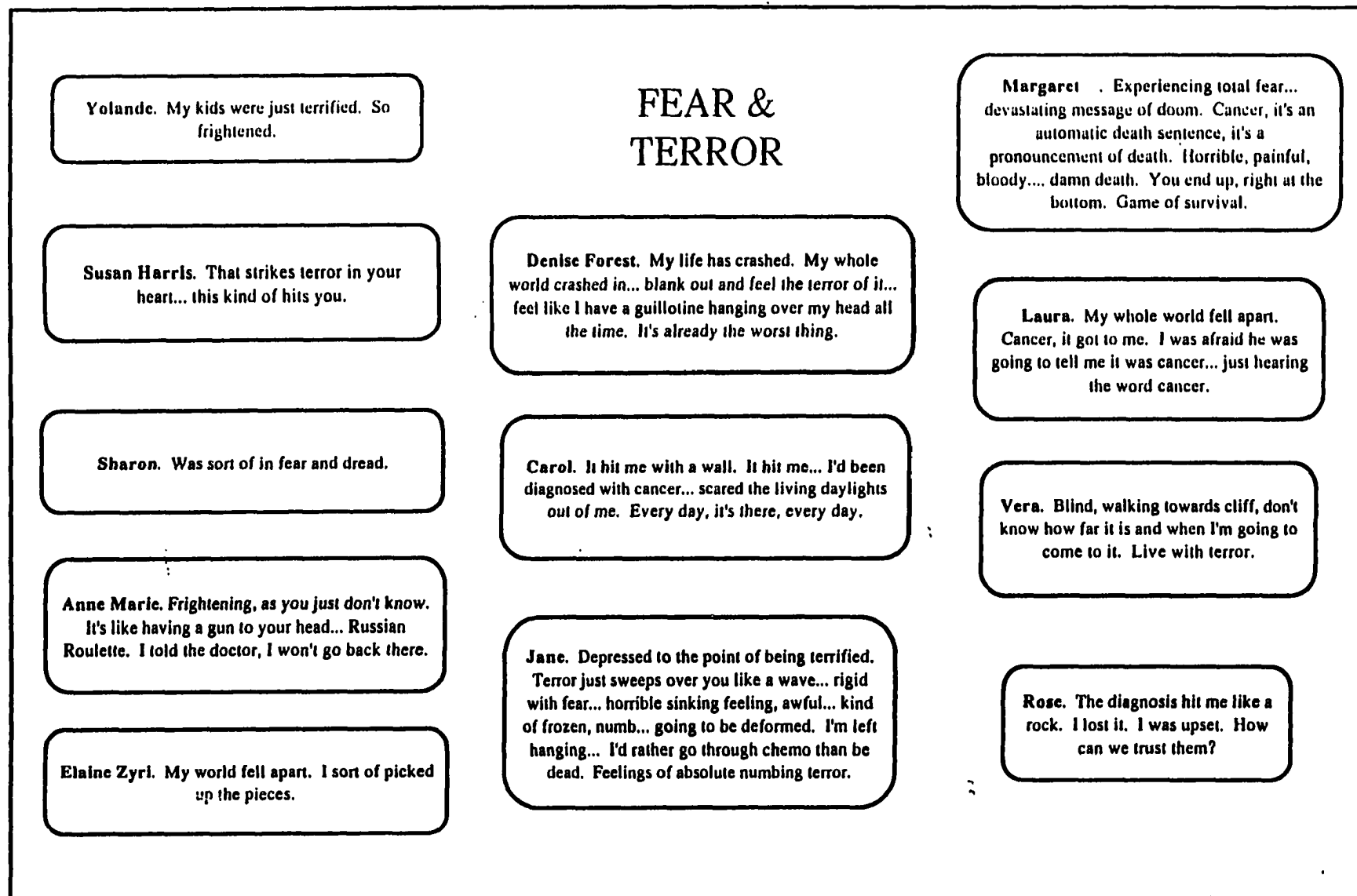
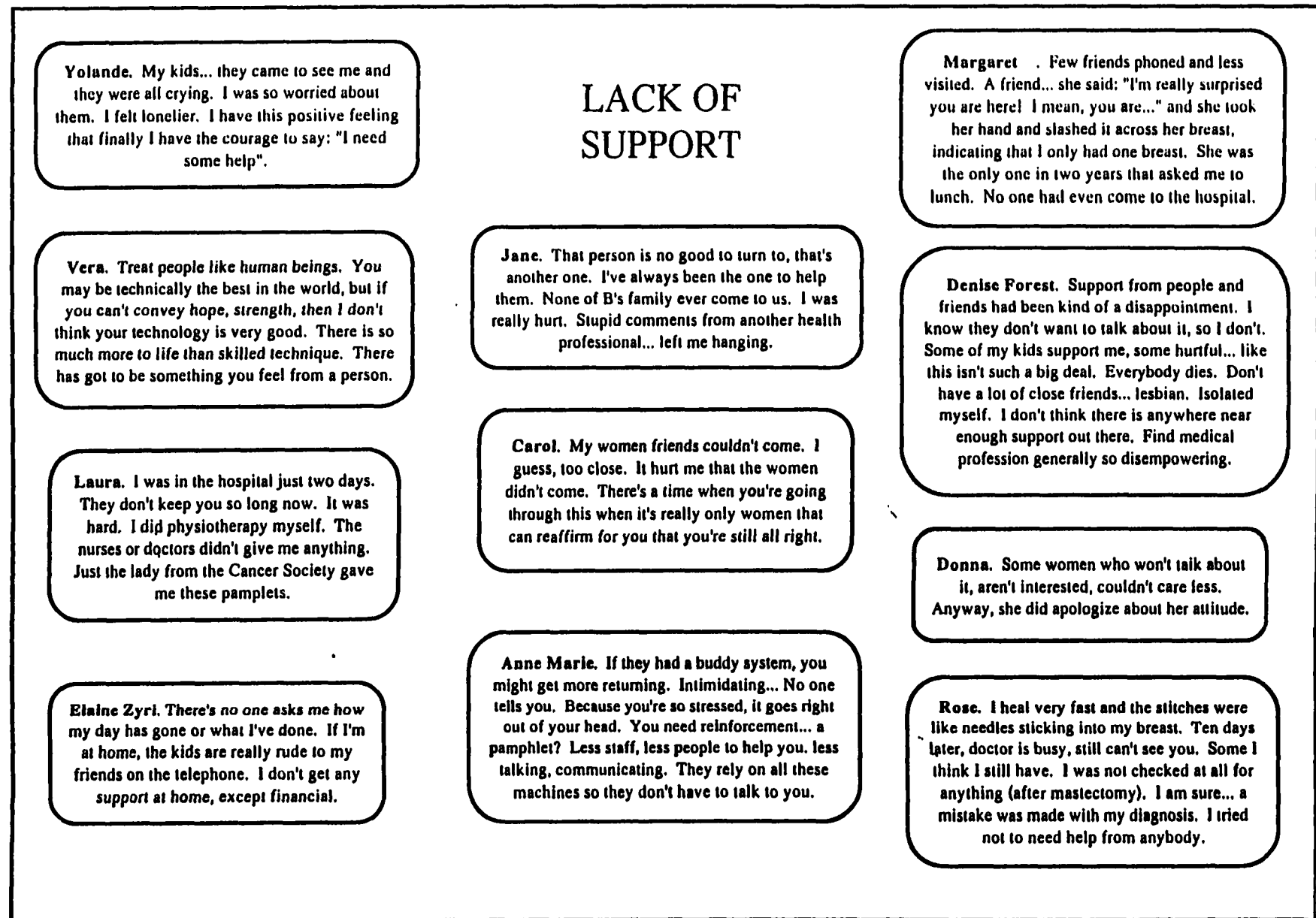


Figure 22. Major Recurrent Themes - Universal Cultural Themes: Lack of Support.



CHAPTER 6: DISCUSSION AND CONCLUSION

This chapter begins with a review of the strengths of the research method of ethnography. Ethnography is both descriptive and holistic (Taylor & Bogdan, 1984). In an attempt to balance a human side of breast cancer research with the biomedical model of research, I want to portray the experiences of clients using their own descriptions, as accurately and holistically as possible. I also wished to use ethnographic methodology which is generally less intrusive than many quantitative research measures. Pyke (1991), in The Science Game, states:

The field study methods contribute sophisticated observational strategies and identification of patterns and classes. . . All scientific methods rely on these basic tools in mapping multi-layered nature . . . A major strength of this method is its nonreactive or unobtrusive character . . . (Agnew & Pyke, 1991, p 152).

Dabbs (1982) suggests that qualitative research involves studying the essential aspects of the thing researched, and that these procedures produce thick, rich descriptions. In this study, ethnographic interview methods resulted in the informants sharing full, detailed descriptions of their experiences. Quantitative research, on the other hand, is about measuring, replicability, using numerical procedures, and generalizing from the controlled research experiment to life, and is the research strategy most used in biomedical research.

Qualitative research is not about measurement and generalization; and as such it has been critiqued for not having scientific rigour in the areas of objectivity, reliability, and validity (Guba & Lincoln, 1987; LeCompte & Goetz, 1982). Nonetheless, Lincoln and Guba (1985) suggest three ways to increase rigour in qualitative research: 1) leaving

a clean, clear audit trail; 2) the confirmability or the accuracy of findings as mirrored back to participants; and 3) fittingness, or the face value as identified by the client's view and the world outside the research situation. Patton (1990, p. 347) suggests that one can increase validity and reliability in qualitative data interpretation and analysis by:

1) making sense of what was said; 2) looking for patterns; 3) putting together what was said (i.e., x fits with y); and 4) integrating what different people have said. The challenge, Patton (1990) suggests, is to make sense out of all the received data, to reduce the amount of information, to identify significant patterns, and to construct a format for writing up the insights and revelations which emerge from the data.

Analysis involves working with data, organizing it, breaking it into manageable units, synthesizing it, searching for patterns discovering what is important and what is to be learned, and deciding what you will tell others (Bogdan & Bilken, 1982, p. 145).

Criteria regarding rigour for qualitative research can be approached through truth value and credibility, applicability and fittingness, consistency and auditability, neutrality (freedom from bias), and confirmability. Confirmability results when auditability, truth value/face value, and applicability are authenticated (Sandelowski, 1986). Readers have the opportunity of checking out the results presented in this ethnography against their own knowledge and experiences.

The use of ethnography in the area of health research offers a different perspective than is typically encountered in this field. Gergen and Gergen (1984) suggest that insight into how individuals perceive the unfolding of their lives can be gained by asking people about their daily lives, and ethnography does just that. As a form of grounded theory

research design, ethnography is a powerful research method involved in explicating large domains of knowledge grounded in the lived experiences of breast cancer clients.

During my tenure working with cancer clients at two different hospitals, one in Victoria, and one in Toronto--the more I listened to, and observed clients, the more it seemed that those who have this experience of breast cancer form a distinct subculture within the dominant culture. When I counselled cancer clients individually and in groups, I noted that clients appeared to divide their worlds into two groups--those who had experienced a diagnosis of cancer (i.e., people like themselves) and those who had not. For example, the one informant who had very little to say about 'lack of support', Donna, may have done so because her two main caregivers were both breast cancer mastectomy survivors. Once I became aware that cancer clients had their own language, rituals, and behaviours, it was clear to me that breast cancer clients form a subculture. This subculture is made up of ordinary people who share a common way of living--that of living with a diagnosis of breast cancer.

An ethnographer seeks out ordinary people with ordinary knowledge and builds on their common experience. Slowly, through . . . interviews, by repeated explanations and through the use of special questions, ordinary people become excellent informants. Everyone, in the course of their daily activities, has acquired knowledge that appears specialized to others . . . Knowledge about everyday life is a common property of the human species (Spradley, p. 25, 1979).

Despite the similarities found amongst cancer clients with other ill-health diagnoses, for example, complaints about pain, inadequate medical care, etc., it seemed that the differences between those who had cancer, and those who had not, were clearly demarcated by a veil of silence. The voices of those who had a diagnosis of cancer

appeared to be muffled by the taboo and stigma which surround cancer in the dominant culture. Taking into account individual, age, and gender differences, it appeared to me that clients with chronic, or serious painful illnesses which were not cancer, were more vocal about the state of their health, medical issues, and treatments (past, present, and future) than were cancer patients. It appeared that each client learned how to be part of the cancer culture separately and individually. Each client knows much tacit knowledge about having cancer largely through individual learning, from experience. Each person finds a way to narrate his or her story within the parameters of a specific culture.

Although cancer clients experience concern from family and friends, individual clients frequently talked of how they felt silenced or even shunned if they talked about or alluded to issues in cancer. Awkwardness in interpersonal interactions and difficulties in communicating were often experienced by cancer clients. Almost all clients I worked with reported that they felt as though the cancer diagnosis resulted in some form of stigma: some older clients stated that they felt others treated them as if they had leprosy; other younger clients said it was as though they had AIDS, i.e., that cancer might somehow be “caught.” Many clients experienced interpersonal situations where the subject of cancer was minimized, discounted, or denied outright. Other clients experienced the diagnosis as a catastrophe (a death sentence with no other possibilities) or observed their family members or friends catastrophize about the cancer diagnosis.

For example, a cancer client shared her diagnosis, which had a favourable prognosis, with her bridge group. At first, she said, everyone murmured concern and caring statements. A few minutes later, however, the client was surprised to hear one of

her bridge buddies refer to her in the third person (“as if I were already dead and gone,” she said): “The next game will be in four weeks, but I suppose G. (client) won’t be here.” This client told me she never again shared with anyone who was not involved with cancer.

All cancer clients spoke about the ambiguities and stresses in their life due to the cancer experience. Most spoke of their fears, their sadnesses, and anger, and the of lack of support that they experienced. All of these ideas were confirmed concretely in the results of the ethnographic analysis as demonstrated by the emergent recurrent cultural themes within the culture of having breast cancer.

One goal of this research is to give the readers of this ethnography some glimpses into the participants’ experiences in their home, work, and health care environments. We were privileged to learn how informants interacted with others, to note how they organized and made sense of their lives (Neimeyer, 1986; Peavy, 1991), to see how they coped within their social arenas in response to the exigencies and stresses of their health situation. Using cross-sectional ethnography and an ethnographic interview method, I have described how participants who have a diagnosis of breast cancer live their lives, how they experience being in the health care environment, and how they describe their reasons for doing what they do. The resultant themes of this research are expected to inform both the theory and practice of cancer counselling. This ethnography, written from the described experiences of those with breast cancer, opens further fields of inquiry for those living and working with cancer, by challenging taboo and reducing stigma. Reading what these cancer clients experienced is of potential benefit to cancer clients and their

families by 'normalizing' the situation and thus reducing that which is taboo and stigmatized. The themes which emerged from the analysis of the collected narrative data form an outline of guidelines for those counselling and/or working with those with breast cancer.

Counselling is normally achieved through words, through language. Language is a basic device for constructing meanings in our lives (Kelly, 1955; Neimeyer, 1986; Peavy, 1990). Linguistics demonstrates that all cultures' language constructs and interprets meanings in ways which enable individuals in that culture to comprehend the reality of the speaker. The dominant narrative of the cancer client is most often dramatically affected with the onset of illness (Mathieson, 1991). Alternative stories are usually constrained by one's culture as well as by the individual's own repertoire of possibilities (White & Epston, 1990). Within subcultures, language is shaped by the exigencies of the differences from the main culture. The achieved goal of this project, using cross-sectional ethnography, reports the verbal description of the lived cultural scenes of those research participants who live with a diagnosis of breast cancer.

Implications for Health, Health-Related Practice and Health Education

From the earliest civilizations, the breast has been a tremendously potent image of womankind. Through war and peace, fashion, religion, art, and literature, it has been revered, praised, lusted after, reviled, and exploited. A powerful representation of beauty, the breast remains a most compelling symbol of our femininity (Stoppard, p. 13,1996).

Because of the cultural emphasis on breasts as feminine symbols, it is difficult to promote the idea that one must check to see if there is a suspicion of cancer. Lack of information for clients on the subject of breast cancer is a major problem. The techniques

for Breast Self-Examination were introduced in the 1950s, but continue to be poorly practised by both physicians and members of the public. Its use is increasing through education programs and promotion in the media. The death rate from breast cancer has not changed since the 1930s when records first began to be kept, suggesting to some women that there is little point in identifying breast cancer (Batt, 1994). What research has shown is that there is a slight reduction in the number of younger women dying of breast cancer, but an increase in older women, thus keeping the overall death rate constant (Harris, et al., 1992). Since the mid-1970s, information about breast cancer has steadily become more available in both the media and in scientific publications, but “the sad truth is that breast cancer research has not shown dramatic treatment benefits” (Batt, 1994, p. 371). The cultural myths around the subject of breast cancer are very slow to change. Hynes, (1994), an environmental engineer, speaks of the mythology of breast cancer treatment:

A legitimizing mythology: The mythology that surrounds orthodox breast cancer treatments is that harsh, aggressive attacks are effective and indeed the only way to combat cancer, even though evidence of progress is a will-o'-the-wisp. Promoting the technology are the two slogans, “early detection is your best protection” and “cancer can be beaten.” The dozens of chemotherapy combinations, strengths and schedules, the increasing precision of radiation and mammography have not fulfilled their promise, but science presses further along the same path with inventive hormonal intervention schemes and the impending genetic technologies. The limits of surgery are now well established, yet elaborate schemes to “improve” breast surgery through breast implants and . . . breast reconstruction and more precise post-lumpectomy radiation continue apace (pp. 205-6).

She continues:

Technology is presented as the dominant approach. For four decades, the single dominant approach to controlling breast cancer has been aggressive, and

increasingly technical, treatment. By combining treatments and moving them back to ever-earlier stages of disease and finally, to women with no sign of disease, the numbers of women treated are increased, independent of whatever real increase in incidence may be occurring (Hynes, cited in Batt, 1994, p. 244).

Sharon Batt, a journalist and survivor of breast cancer says:

Like most people I know, I once believed that mammography unerringly found cancerous breast lumps years before they could be felt, that existing treatments would cure the disease, that women who got breast cancer soon put the disease behind them and went cheerfully on with their lives. The gap between these beliefs and reality still takes my breath away. How could such a distorted view be entrenched and sustained for so long?

The mythology is powerful and has been constructed over a period of decades: it sustains the belief that an arsenal of sophisticated biotechnical weaponry has breast cancer virtually beaten. The information that reaches the public is groomed not only by the medical profession but by a variety of powerful interest groups: cancer charities, multinational companies and the media. Each filters the truth in a way that complements the others and serves its own needs (Batt, 1994, p. 207-8).

For a holistic approach to investigating all sides of the issue of breast cancer, it is essential to incorporate the experiences of those 'who have been there,' with biomedical research. This ethnographic research method extends the knowledge of how 13 women perceive their experiences of breast cancer. From their received narratives, themes were merged into a counselling schedule or guideline for counsellors or teachers of counsellors.

This information teaches us, informs us, while at the same time speaking for a group where individuals often feel unheard or silenced. I propose that variations on this guide be used by counsellors as a reference for the counselling process and also as a handout for newly diagnosed breast cancer patients.

Breast Cancer Counselling Guidelines

1. Ambiguity and Stress (see Figures 9 and 19)

Health care providers may find it instructive to acknowledge clients' attempts to diffuse stress by providing listening time. Although stress reduction and relaxation techniques are valuable in themselves, and are typically offered at cancer agencies, the women repeatedly questioned ambiguities in various aspects of what was going on in their treatment schedule or procedures. Feedback from clients to the health care providers may, in time, also effect changes.

2. Dehumanization (see Figure 10)

Clients want to be treated with more care and personal attention by all members of the medical and care provider professions. When an individual is challenged with the changes which result from illness, such as experiencing dependence on professional experts, counsellors can provide support in identifying experiences which are objectifying. Further, counsellors are able to provide support for the client who wishes to challenge such experiences with the professional concerned. Providing counselling services is only one aspect of this need. Further education of all those who work with cancer patients on how seriously the issue of

dehumanization affects clients may create positive change in how clients are being treated by all those working with breast cancer clients.

3. Disempowerment and Trivialization (see Figure 11)

Clients complained about the general disempowerment which comes with a diagnosis of cancer in our culture. As this is ethnography, where the researcher's biases are bracketed and put aside, I used only what emerged in the women's narratives. Future research directions could include work on using Feminist Theory for empowerment. It is interesting to note the more general experience I had while working in the cancer clinics: both men and women in our culture are disempowered when they are sick and feel no longer in control of their lives. The cultural trivialization of any illness process appears to be general. Thus counselling is of value to validate what is happening for any cancer client, regardless of age, gender, or cultural background.

4. Shame and Stigma (see Figure 12)

Clients summed up this experience of shame and/or stigma, which they perceived both externally and internally, by taking the responsibility or blame for "getting cancer." Exploring this issue as being an aspect of the dominant culture's attitude toward illness, and cancer in particular, with cancer patients is essential. Letting

go of the cultural mandate that one is largely responsible for one's illness is a step forward in working on personal well-being. Feeling good about oneself is important to the health recovery process.

5. Coping (see Figure 13)

Coping styles are unique to the personality of each client. Counselling on control issues are important since many individuals experience a sensation of being out of control when the 'experts' have charge of one's life, with tests and test results and treatments. Since there are strategies which can be learned, (such as are offered at psychologist's Alastair Cunningham's Coping Skills Clinic at Princess Margaret Cancer Hospital in Toronto) counselling can teach these skills in addition to enhancing skills the client is currently using.

6. Minimizing and Denial (see Figure 14)

Our culture uses minimalizing and denial around issues of illness, pain, palliative care, and death, so many clients and their families are adept at using these defences. There are books such as No time for nonsense: Self-help for the seriously ill (Jevne & Levitan, 1989) to support those who do want to work with these issues. However, there are times when the individual who is ill simply wants to talk, rather than read. As defences wear thin, counselling can be very

productive, especially when the prognosis is not what the client and her family expect or want to hear.

7. It (Cancer) Changes Everything (see Figure 15)

Ready or not, a diagnosis of breast cancer changes the life of the individual and her family for the duration. There is no cure for cancer, only the possibility of remission. The notion ‘if you survive five years you are cured’ is a myth.

Metastases occur mysteriously and at any time, regardless of how much time has passed ‘in remission’ (Batt, 1994; Love, 1995). Since change and living with ambiguity are often difficult to live with comfortably, counselling discussions about change, about the unknown, and how to prepare and work with these issues, are practical.

8. The Game of Survival (see Figure 16)

The cultural myth that cancer equals death often transforms this diagnosis into either a depression or a fierce process of fighting for life or both. The threat to one’s life is a serious existential issue, and the counselling process is valuable for exploring how the client processes and works with her life being endangered.

9. Doctor is God and He Takes Charge of Your Life (see Figure 17)

Loss is a recurrent theme with clients of breast cancer; loss of independence is most serious as it affects all aspects of one's life. The reality that an individual's health is largely in the hands of those in the medical and treatment field, in test results and in treatment protocols, is very frightening. Loss of control over one's life or one's destiny is a constant theme. In counselling women with breast cancer, I found that it is a critical learning, that, though I may have a life-threatening illness, I still maintain control over many aspects of my life. Counsellors may also be available to support the client when she challenges the paternalism and sexism which may occur in a male dominated profession such as medicine.

10. Sadness and Anger (see Figure 20)

All clients reported feeling the primary emotions of sadness and anger at various points after their diagnoses. Each client queries "Why me?" and the unfairness of life. Clients search the past and the present for cause for this terrible effect (a diagnosis of breast cancer) and when they cannot find cause, strong feelings emerge. Counselling provides a place to honour all feelings and to process personal work arising from the past and the present.

11. Fear and Terror (see Figure 21)

All clients stated they experienced fear: fear of the unknown, fear of pain and suffering, fear of dying, fear of more loss. The counselling venue offers appropriate support for working with these feelings, for both the client and her family, separately and/or together.

12. Lack of Support (see Figure 22)

Clients spoke repeatedly of experiencing lack of support. Counselling can teach communication skills which may assist clients in challenging the cultural norm of avoidance of those with cancer. Individuals stated they wanted to talk about their feelings, about not being understood, about not being accepted in the same ways since their diagnosis, about being rejected and/or abandoned. These issues arise for both the client and those close to her. Counselling offers a valuable contribution in providing the potential skills for changing lack of support to support.

Conclusion and Further Directions for Research

This cross-sectional ethnography report has produced a counselling guideline of tacit and explicit themes which may be utilized in counselling cancer clients and in teaching counsellors. The researcher and reader has learned what it

is like to live with breast cancer for a cross-section of 13 women in the population of those who have been diagnosed with breast cancer.

Further directions for research include examining the metaphors and images emerging from those who have breast cancer for enhanced counselling assistance. Future research could also investigate and review all recommendations from research participants for other breast cancer patients, their families and those in the medical profession.

A personal reflection on the research process reminds me of an ancient Chinese Proverb which says that prediction is notoriously tricky, especially when it is for the future. Nonetheless, I predict that the use of applied ethnography in health research will grow. I also predict, along with Werner and Schoepfle (1987), that cross-sectional ethnography designs of increasing sophistication will become commonplace.

References

- Agar, M. H. (1986). Speaking of ethnography. Beverly Hills, CA: Sage Publications.
- Agar, M. H. (1996). The professional stranger: An informal introduction to ethnography. San Diego, CA: Academic Press.
- Agnew, N., & Pyke, S. W. (1991). The science game: An introduction to research in the social sciences (5th ed.), Englewood Cliffs, NJ: Prentice Hall.
- Alexander, J. (1989). Further considerations. The Clinical Social Work Journal, 17(4), 321-324.
- Andrulis, I. L. (1997). Prognostic markers for node-negative breast cancer. Paper presented at the World Conference on Breast Cancer, Kingston, Canada.
- Atkinson, P. (1992). Understanding ethnographic texts: Qualitative Research Methods. London: Sage Publications.
- Bartos, R. (1982). The moving target: Women as consumers. New York: The Free Press, Macmillan.
- Batt, S. (1994). Patient no more: The politics of breast cancer. Charlottetown, PEI.: gynergy books.
- Beck, A. T. (1976). Cognitive therapy and the emotional disorders. New York: International Universities Press.
- Behar, R. (1991). The body in the woman, The story in the woman: A book review and personal essay. In L. Goldstein (Ed.), The female body, figures, styles, speculations. Ann Arbor, MI: The University of Michigan Press.

- Bernard, H. R. (1988). Research methods in cultural anthropology. Newbury Park, CA: Sage.
- Bogdan, R., & Bilken, S. (1982). Qualitative research for education: An introduction to theory and methods. Boston: Allyn and Bacon.
- Boyle, J. (1994). Styles of ethnography. In Janice M. Morse, (Ed.) Critical Issues in Qualitative Research Methods., Thousand Oaks, Ca.:Sage Publications.
- Brady, J. (1997, July). Politics of cancer: The flow of money. World Conference on Breast Cancer. Kingston, Canada.
- Bramwell, L. (1989). Cancer nursing--a problem-finding survey. Cancer Nursing, 12, 320-328.
- Brookes, A. L. (1992). Feminist pedagogy: An autobiographical approach. Halifax, NS: Fernwood Publishing.
- Brown, G., Bryne, C., Roberts, J., Fitch, M., Corey, P., & Arpin, K. (1988). Nursing Research, 37, 368-373.
- Bunston, T. (1997, July). The psychosocial needs of women with breast cancer. Paper presented at the World Conference on Breast Cancer, Kingston, Canada.
- Callan, D. B. (1989). Hope as a clinical issue in oncology social work. Journal of Psychosocial Oncology, 7(3), 31-46.
- Campbell, S. H. (1984). The meaning of the breast cancer/mastectomy experience. Unpublished master's thesis, University of British Columbia, Vancouver, Canada.
- Carter, B. J. (1989). A phenomenological study of survivors of adult cancer. Unpublished doctoral dissertation, University of California.

- Cassileth, B. R., Lusk, E., Walsh, W., Altman, H., & Pisano, M. (1987). Psychosocial correlates of unusually good outcome 3 years after diagnosis. Proceedings of American Social Clinical Oncology, 253.
- Cella, D. F., Jacobsen, P. B., & Lesko, L. M. (1989). Research methods in psychooncology. In J. C. Holland & J. H. Rowland (Eds.), Handbook of psychooncology: Psychological care of the patient with cancer. Oxford: Oxford University Press.
- Collins, R., Taylor, S. E., & Skokan, L. A. (1990). A better world or a shattered vision? Changes in life perspectives following victimization. Social Cognition, 8, 263-285.
- Cope, D. G., (1995). Functions of a breast cancer support group as perceived by the participants: An ethnographic study. Cancer Nursing, 18, 472-8.
- Cousins, N. (1976). Anatomy of an Illness [as perceived by the patient]. New England Journal of Medicine, 295, 1458-1463.
- Cunningham, A. J. (1988). From neglect to support to coping: The evolution of psychosocial intervention for cancer patients. In B. L. Cooper (Ed.) Stress and Breast Cancer. Toronto, ON: John Wiley & Sons.
- Cunningham, A. J., & Tocco, E. K. (1989). A randomized trial of group psychoeducational therapy for cancer patients. Patient Education and Counselling, 14, 101-114.

- Cunningham, A. J., Lockwood, G. A. & Cunningham, J. A. (1991). A relationship between perceived self-efficacy and quality of life in cancer patients. Patient Education and Counselling, 17, 71-78.
- Dabbs, J. M., Jr. (1982). Making things visible. In J. Van Manen, J. M. Dabbs, Jr., & R. F. Faulkner (Eds.), Varieties of qualitative research. (pp.31-66). Beverly Hills, CA: Sage Publishing.
- Decker, T. W., Cline-Elsen, J., & Gallagher, M. (1992). Journal of Clinical Psychology, 48, 388-393.
- Denzin, N. K. (1987). The research act. Chicago: Aldine Publishing.
- Denzin, N. K. (1989). The research act: A theoretical introduction to sociological methods. New York: Prentice Hall.
- Derdiarian, A.K. (1986). Informational needs of recently diagnosed cancer patients. Cancer Nursing, 11, 274-282.
- Derogatis, L. R., Abeloff, M. D., & Melisaratos, N. (1983). Psychological coping mechanisms and survival time in metastatic breast cancer. Journal of the American Medical Association, 242, 1504-8.
- Diekmann, J. M. (1989). An evaluation of selected "I Can Cope" programs by registered participants. Cancer Nursing, 11, 274-282.
- Dow, K.H. (1991). The growing phenomenon of cancer survivorship. Journal of Professional Nursing, 7, 54-61.

- Dunaway, F. W., Hueston, W. J., & Clevinger, L. (1995). An exploratory study of the experiences of rural women with breast cancer. Journal of Kentucky Medical Association, 93, 241-5.
- Edwards, J.R., Cooper, C.L., Pearl, S.G., & de Paredes, E.S.(1990). The relationship between psychosocial factors and breast cancer. Behavioural Medicine. 16(1), 5-14.
- Edgar, L., Rosberger, Z., & Nowlis, D. (1992). Coping with cancer during the first year after diagnosis: Assessment and intervention, Cancer, 69, 817-828.
- Eisenberg, D. M., Kessler, R. C., Foster, C., Norlock, F. E., Calkins, D. R., & Delbanco, T. L. (1993). Unconventional medicine in the United States: Prevalence, costs and patterns of use. New England Journal of Medicine, 328, 246-252.
- Elliott, B., Rahimi, N., Tremblay, E., Shenoy, P., Rossiter, J., & Saulnier, R. (1997, July). Hepatocyte Growth Factor in Survival, Growth and Metastasis of Breast Carcinomas: A Potential Target for Therapeutic Intervention. World Conference on Breast Cancer. Kingston, Canada.
- Engel, G. L.(1977). The need for a new medical model: A challenge for biomedicine. Science, 196, 129-36.
- Ersek, M. (1986). Stress and cancer: Elusive connections. Oncology Nursing Forum, 13(5), 49-56.
- Fawzy, F.I., Fawzy, N.W., Hyun, C.S., Elashoff, R., Guthrie, D., Fahey, J.L., & Morton, D.L. (1993). Malignant melanoma: Effects of an early structured psychiatric

intervention, coping, and affective state on recurrence and survival 6 years later.

Archives of General Psychiatry, 50, 681-689.

Ferguson, B.F. (1990). Towards an understanding of my transformational experience with cancer. Unpublished Master of Arts Thesis, University of Victoria, Victoria, B.C., Canada.

Ferrans, C. E. (1990). Development of a quality of life index for patients with cancer. Oncology Nursing Forum Supplement, 17(3), 15-19.

Fetterman, D. M. (1989). Ethnography step by step. Newbury Park, CA: Sage Publications.

Fiore, N. (1979). Fighting cancer -- One patient's perspective. New England Journal of Medicine, 300, 284-289.

Fiore, N. (1984). The road back to health. New York: Bantam Books.

Folkman, S., & Lazarus, R. S. (1988). Manual for the Ways of Coping Questionnaire. Palo Alto, CA: Consulting Psychologists Press.

Fosket, J., Lafia, C., & Rose, A. (1997, July). Cultural metaphors and gender discourses on women's bodies: Media and breast cancer from 1913 to 1996. Paper presented at the World Conference on Breast Cancer, Kingston, Canada.

Fredette, S.L. (1990). A model for improving cancer patient education. Cancer Nursing, 13(4), 207-215.

Freud, S. (1953). Thoughts for the time on war and death. In J. Strachey, (Ed.). The Complete Psychological Works. Vol. XIV, London: Hogarth.

Frankl, V. (1962). Logotherapy. New York: Bantam.

- French, M. (1992). The war against women (sex discrimination against women). New York: Simon & Schuster.
- Garcia, J. S. Jr., Cristal-Luna, G., Li, R.K., Uai, R., Gonzalez, Y. M., Tarmayo, M. B., Masadao, F. R., Lola, C. J., & Matumog, C. N. (1997, July). Depressive Symptoms in Cancer Patients on Chemotherapy. Paper presented at the World Conference on Breast Cancer, Kingston, Canada.
- Gergen, K. J., & Gergen, M. M. (1984). The social construction of narrative accounts. In K. Gergen & M. Gergen (Eds.), Historical social psychology, Hillsdale, NJ: Lawrence Erlbaum.
- Gergen, K. J., & Gergen, M. M. (1988). Narratives and the self as relationship. In K. Gergen & M. Gergen (Eds.), Advances in experimental social psychology, San Diego, CA: Academic Press Inc.
- Gerits, P., & De Brabander, B. (1997). Psychosocial predictors of acute stress symptoms in breast cancer. Conference of the European Health Psychology Society, Bordeaux, France.
- Gilka, M. D. (1997, July). Opportunities to reduce breast cancer incidence and improve treatment outcomes by applying full knowledge of risk factors and protective factors. Paper presented at the World Conference on Breast Cancer, Kingston, Canada.
- Glaser, B. G. & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research, Chicago: Aldine Publishing Co.

- Goetz, J. P., & Lecompte, M. D. (1984). Ethnography and qualitative design in educational research. Orlando: Academic Press.
- Gotay, C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. Social Science and Medicine, 18, 605-613.
- Gotcher, J., & Edwards, R. (1990). Coping strategies of cancer patients: Actual communication and imagined interactions. Health Communication, 2, 255-266.
- Grahn, G., & Johnson, J. (1990). Learning to cope and living with cancer: Learning needs assessment in cancer patient education. Scandinavian Journal of Caring Sciences, 4(4), 173-181.
- Greer, S., & Morris, T. (1974). Psychological attributes of women who develop breast cancer: A controlled study. Journal of Psychosomatic Research, 19, 147-143.
- Greer, S., Morris, T., & Pettingale, K. W. (1979). Psychological response to breast cancer: Effect on outcome. Lancet, 2, 785-87.
- Grimm, P. M. (1989). Hope, affect, psychological status and the cancer experience. Unpublished Doctoral Dissertation, University of Maryland at Baltimore.
- Guba, E. G., & Lincoln, Y. S. (1987). Effective evaluation. San Francisco: Jossey-Bass.
- Guba, E. G., & Lincoln, Y. S. (1989). Fourth generation evaluation. Newbury Park, CA: Sage Publications.
- Hall, E. T. (1992). An anthropology of everyday life. New York: Anchor Books.
- Harris, J. R., Lippman, M. E., Veronesi, U., & Willett, W. (1992). New England Journal of Medicine, 327(5). 319-320.

- Hart, J. (1993). Love, Judy: Letters of hope and healing for women with breast cancer. Berkeley, CA: Conari Press.
- Hart, K. (1986). Stress encountered by significant others of cancer patients receiving chemotherapy. Omega Journal of Death of Dying, 17(2), 151-167.
- Herth, K. A. (1989). The relationship between level of hope and level of coping response and other variables in patients with cancer. Oncology Nursing Forum, 16(1), 67-72.
- Hilton, B. A. (1988). The phenomenon of uncertainty in women with breast cancer. Issues in Mental Health Nursing, 9(3), 217-238.
- Holland, J. C. (1989). Fears and abnormal reactions to cancer in physically healthy individuals. In J. C. Holland & J. H. Rolland (Eds.), Handbook of Psychooncology: Psychological care of patients with cancer. Oxford: Oxford University Press.
- Holland, J. C., Korzun, A. H., Tross, S., Cella, D. F., Norton, L., Wood, W. (1986). Psychosocial factors and disease-free survival in Stage II breast cancer. Proceedings of American Social and Clinical Oncology, 237.
- Holland, J.C., & Rolland, J. H. (1989). Breast cancer. In J. Holland & J. Rolland (Eds). . Handbook of Psychooncology: Psychological care of patients with cancer. (pp.188-207). Oxford:Oxford University Press.
- Hopkins, M. B. (1986). Information-seeking and adaptational outcomes in women receiving chemotherapy for breast cancer. Cancer Nursing, 9(5), 256-262.

- Howell, D. (1986). The impact of terminal illness on the spouse. Journal of Palliative Care, 2,(1), 22-30.
- Inglefinger, F.J.(1975). Cancer! Alarm! Cancer! (Editorial). New England Journal of Medicine, 293, 1319-20.
- Jamison, R. N., Burish, T.G., & Wallston, K. A. (1987). Psychogenic factors in predicting survival of breast cancer patients. Journal of Clinical Oncology, 5, 768-72.
- Jevne, R.F., & Levitan, A. (1989). No Time for Nonsense. Self-Help for the seriously ill. San Diego, California:LuraMedia
- Johnson, J.E., & Lauver, D.R. (1989). Alternative explanations of coping with stressful experiences associated with physical illness. Advances in Nursing Science.11(2), 39-52.
- Johnson, J., & Klein, L., (1988). I can cope: Staying healthy with cancer. Minneapolis, MN: DCI Publishing.
- Kesselring, A. (1990). The experienced body: when taken-for-grantedness falters: a phenomenological study of living with breast cancer, Unpublished doctoral dissertation, University of California.
- Kelly, G. A. (1955). The psychology of personal constructs. New York: Norton.
- Key, W. B. (1976). Media sexploitation. Psychological aspects of advertising. London: Prentice-Hall.
- Kierkegaard, S. (1990). The sickness unto death. (1848). In H. Hong & E Hong, (Eds.) Princeton, New Jersey:Princeton University Press.

- Kilbourne, J. (Producer), (1979). Killing us softly: Advertising's image of women [Film].
(Available from: Cambridge Documentary Films. Cambridge, MA.)
- Kilbourne, J. (Producer), (1987). Still killing us softly. [Film]. (Available from
Cambridge Documentary Films, Cambridge, MA.)
- Kimball, C. (1981). The biopsychosocial approach to the patient. Baltimore, MD:
Williams & Wilkins.
- Kobasa, S. C. (1979). Stressful events, personality, and health: An inquiry into hardiness.
Journal of Personality and Social Psychology, *37*, 1-11.
- Kopp, S. (1979). What took you so long? An assortment of life's everyday ironies. Palo
Alto, CA: Science and Behavior Books.
- Kubler-Ross, E. (1969). On Death and dying. New York: Macmillan
- Lazarus, R. S., & Folkman, S. (1984). Stress appraisal and coping. New York: Springer.
- LeCompte, M. D., & Goetz, J. P. (1982). Problems of reliability and validity in
ethnographic research. Review of Educational Research, *52*, 31-60.
- Lewis, F. M., & Deal, L. W. (1995). Balancing our lives: A study of the married couple's
experience with breast cancer recurrence. Oncology Nursing Forum, *22*, 943-53.
- Lipowski, Z. J. (1970). Physical illness, the individual and the coping processes.
Psychiatry Medicine, *1*, 91-102.
- Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. Beverley Hills, CA: Sage
Publishing
- Lorde, A. (1990). The cancer journals. San Francisco: aunt lute books.

- Love, S., (1995). Breast Cancer Update, The Breast Cancer Foundation Keynote Address, Hotel Vancouver, Vancouver, B.C., Canada
- Love, S. (1990). Dr. Susan Love's breast book. New York: Addison-Wesley Publishing
- MacPhee, R. (1994). Picasso's woman: A breast cancer story. Vancouver, BC: Douglas & McIntyre.
- Mack, R. M., (1984). Lessons from living with cancer. New England Journal of Medicine, 311, 1640-1644.
- Maddi, S. R., & Kobasa, S. C. (1984). The hardy executive: Health under stress. Homewood, IL: Dow Jones-Irwin.
- Martens, N., & Davies, B. (1990). The work of patients and spouses in managing advanced cancer at home. Hospice Journal: Physical, Psychosocial and Pastoral Care of the Dying, 6 (2), 55-73.
- Massie, M.J., & Holland, J.C. (1989). Overview of normal reactions and prevalence of psychiatric disorders. In J. Holland and J. Rowland, (Eds.) Handbook of Psychooncology: Psychological Care of the Patient with Cancer. (pp. 273-282). Oxford: Oxford University Press.
- Mathieson, C. M. (1991). Renegotiating identity: Cancer narratives. (Unpublished doctoral dissertation. The University of Calgary, Calgary, Alberta, Canada.
- Mathieson, C. M., & Stam, H. J. (1991). What good is psychotherapy when I am ill? Psychosocial problems and interventions with cancer patients. In C. L. Cooper & M. Watson (Eds.), Cancer and Stress: Psychological, Biological and Coping Studies. Toronto, ON: John Wiley & Sons.

- Mathews, H. F., Lannin, D.R., & Mitchell, J. P. (1994). Coming to terms with advanced breast cancer: Black women's narratives from eastern North Carolina. Social Science and Medicine, 38, 789-800.
- Matt, D., Sementilli, & M. Burish, T. (1988). Denial as a strategy for coping with cancer. Special Issue: Behavioral medicine and the mental health counsellor. Journal of Mental Health Counselling, 10, 136-144.
- McIntyre, M.R. (1988). An exploration of the experience of the patient with cancer pain. Unpublished doctoral dissertation, University of British Columbia, Vancouver, B.C., Canada.
- Meichenbaum, D., & Turk, D. (1976). The cognitive-behavioral management of anxiety, anger and pain. In P.O. Davidson (Ed.), The Behavioral Management of Anxiety, Depression and Pain . New York: Bruner-Mazel.
- Mermelstein, H.T. (1991). Psychotherapy by telephone. A therapeutic tool for cancer patients. Psychosomatics, 32(4), 407-412.
- Moch, S. D. (1988). Health in illness: Experiences with breast cancer. Unpublished doctoral dissertation, University of Minnesota.
- Monat, A. & Lazarus, R. S. (1991). Stress and coping. New York: Columbia University Press.
- Moorey, S., & Greer, S. (1989). Psychological therapy for patients with cancer: A new approach. Oxford: Heinemann Medical Books.
- Morris, T., Greer, H.S., & White, P. (1977). Psychological and social adjustment to mastectomy: A two year follow-up study. Cancer, 40, 2381-2387.

- Morse, J.M. (1992). Ethnography. In J.M. Morse (Ed.) Qualitative health research. Newbury Park, CA: Sage.
- Mumford, E. (1986). My Breast. Plains Poetry. Bismark, N.D.:Stronghold Press.
- Neimeyer, R. A. (1986). Personal construct therapy. In W. Dryden & W. Golden (Eds.), Cognitive-behavioral approaches to psychotherapy. London: Harper & Row.
- Nin, A. (1973). Imagination. In P. Jason (Ed.), Anais Nin reader. Chicago, IL: The Swallow Press.
- Northouse, L. L., & Wortman, C. B. (1990). Models of helping and coping in cancer care. Journal of Patient Education and Counselling, 15, 49-64.
- O'Donnell, J. F., Coughlin, C.T., & LeMarbre, P. J., (1992). Oncology. Baltimore, MD: Williams & Wilkins.
- Olivotto, I., Gelmon, K., & Kuusk, U. (1995). Intelligent patient guide to breast cancer: All you need to know to take an active part in your treatment. Vancouver, BC: Intelligent Patient Guide.
- Padilla, G. V., Ferrell, B., Grant, M. M., & Rhiner, M. (1990). Defining the content domain of quality of life for cancer patients with pain. Cancer Nursing, 13(2), 108-115.
- Patterson, J. T. (1987). The dread disease: Cancer and modern American culture. Cambridge: Harvard University Press.
- Patton, M. Q. (1990). Qualitative evaluation and research methods (2nd ed.) Newbury Park, CA: Sage Publications.

- Peavy, R.V. (1990, May). Reflective model of counselling. Paper presented at the Ninth International Human Science Research Conference, Universite Laval, Quebec.
- Peavy, R.V. (1991). Constructivism and the practice of storied counselling. The Centre for Studies in Worklife and Career Counselling, British Columbia:University of Victoria, Canada.
- Pennebaker, J. W., (1990). Opening up: The healing power of confiding in others. New York: Avon Books.
- Peteet, J.R. (1984). Emotional aspects of breast cancer and its treatment. In C. Pfeiffer & J. Mulliken (Eds.), Caring for the patient with breast cancer: An interdisciplinary/multidisciplinary approach. Washington: Reston Publishing.
- Pikunas, K. (1997, July). Anticipating diagnosis of cancer: The experience of anxiety and depression and its relationship to coping. Paper presented at the World Conference on Breast Cancer, Kingston, Canada.
- Pritzker, J. K. (1988). The development and formative evaluation of a psychoeducationally based program for post-mastectomy women. Unpublished doctoral dissertation, University of Georgia.
- Quashigah, A. (1997). Breast Cancer and Social Life. Paper presented at the World Conference on Breast Cancer, Kingston, Canada.
- Razack, S. (1993). Storytelling for social change. In H. Bannerji (Ed.), Returning the gaze: Essays on racism, feminism & politics (pp. 83-100), Toronto, ON: Sister Vision Press.

- Reiser, D. E. & Rosen, D. H. (1984). Medicine as a human experience. Baltimore, MD: University Park Press.
- Roberts, C.S., Elkins, N.W., Baile, W. F., & Cox, C.E. (1989). Integrating research with practice: The psychosocial impact of breast cancer. Health and Social Work, 14, 261-268.
- Roberts, D. C. (1992). Emotional distress, expression of emotion, and immune function in cancer patients: A test of the association between psychological responses and cancer progression. Unpublished doctoral dissertation, The University of Iowa.
- Roud, P. (1987). Psychosocial variables associated with the exceptional survival of patients with advanced malignant disease. Journal of the National Medical Association, 79, 97-102.
- Rowland, J. H. (1989). Intrapersonal Resources: Coping. In J. Holland & J. Rolland (Eds.), Handbook of psychooncology: Psychological care of the patient with cancer. (pp. 44-57). Oxford: Oxford University Press.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances of Nursing Science, 8, 27-37.
- Schwartz, H., & Jacobs, A. (1979) Qualitative sociology. New York: The Free Press.
- Selye, H. (1946). The general adaptation syndrome and the diseases adaptation. Journal of Clinical Endocrinology, 6, 117-120.
- Selye, H. (1974). Stress without distress, Philadelphia: Lippincott Press.
- Selzer, R. (1976). Mortal lessons: Notes of the art of surgery. New York: Simon & Schuster.

- Shaw, C. R. A. (1988). Exploration of experiences of women during the initial treatment for breast cancer. Unpublished doctoral dissertation, The University of Wisconsin, Milwaukee.
- Siegel, B. (1989). Love, medicine and miracles. New York: Harper & Collins.
- Silberfarb, P.M., & Greer, S. (1982). Psychological concomitants of cancer: clinical aspects. American Journal of Psychotherapy, 36, 470-478.
- Silverman, D., Gartrell, N., Aronson, M., Steer, M., & Edril, S. (1983). In search of the biopsychosocial perspective: An experiment with beginning medical students. American Journal of Psychiatry, 140, 1154-59.
- Simonton, O. C., Simonton, S. M., & Creighton, J. L. (1978). Getting well again. Los Angeles: J. P. Tarcher.
- Sontag, S. (1978). Illness as metaphor. New York: Farrar, Straus & Giroux.
- Spiegel, D. (1989). Psychosocial interventions with cancer patients. Journal of Psychosocial Oncology, 3, 83-95.
- Spiegel, D., Bloom, J. R., Kraemer, H., & Gottheil, E. (1989). Effect on psychosocial treatment on survival of patients with metastatic breast cancer. The Lancet, 10, 888-891.
- Spradley, J. P. (1979). The ethnographic interview. New York: Holt, Rinehart, & Winston.
- Spradley, J. P. (1970). You owe yourself a drunk. An ethnography of urban nomads. Boston: Little Brown.

- Stanton, C. M. (1992). Psychobiological study of eight cancer patients. Unpublished doctoral dissertation, The Union Institute.
- Starck, P. (1983). Patients' perceptions of the meaning of suffering. International Forum for Logotherapy, 6(2), 110-116.
- Stolar, G. E. (1982). Coping with mastectomy: Issues for social work. Health and Social Work, 7(1), 26-34.
- Stoppard, J. (1996). The Breast Book. Oxford: Oxford University Press.
- Stoudemire, A. (1983). The onset and adaptation to cancer: Psychodynamics of an ill physician. Psychiatry, 46, 377-386.
- Sultana, R. (1997, July). Social taboos and un-named disease. Paper presented at the World Conference on Breast Cancer, Kingston, Canada.
- Taerk, G. (1983). Psychological support of oncology nurses: A role for the liaison psychiatrist. Canadian Journal of Psychiatry, 28, 532-535.
- Taylor, E. J. (1992). The search for meaning among persons living with recurrent cancer. Philadelphia, PA: University of Pennsylvania Press.
- Taylor, S. E., Lichtman, R. R., & Wood, J. V. (1984). Attributions, beliefs about control, and adjustment to breast cancer. Journal of Personality and Social Psychology, 46, 489-502.
- Telch, C. F. & Telch, M. J. (1986). Group coping skills instruction and supportive group therapy for cancer patients: A comparison of strategies. Journal of Consulting and Clinical Psychology, 54, 802-808.

- Tesch, R. (1990). Qualitative research: Analysis types and software tools. New York: The Falmer Press.
- Theorell, T. (1989). Spontaneously occurring stressors. In H. Weiner, I. Florin, R. Murison, & D. Hellhammer (Eds.), Frontiers of stress. (pp. 111-121). Toronto: Huber.
- Thorne, S. E. (1991). Methodological orthodoxy in qualitative nursing research: analysis of the issues. Qualitative Health Research, 1, 178-199.
- Van Manen, M. (1984). Practicing phenomenological writing. Phenomenology & Pedagogy, 2, 36-69.
- Van Manen, M. (1990). Researching lived experience. London, ON: The Althouse Press.
- Van Manen, J. (1984). Practising phenomenological writing. Phenomenology and Pedagogy, 2(1), 36-6.
- Van Manen, J. (1988). Tales of the field: On writing ethnography. Chicago, IL: University of Chicago Press.
- Visweswaran, K. (1994). Fictions of feminist ethnography. Minneapolis, MN: University of Minnesota Press.
- Von Eckartsberg, R. (1986). Existential-phenomenological research approaches in psychology. Washington, DC: The Center for Advanced Research in Phenomenology.
- Wadler, J. (1992). My breast: One woman's cancer story. New York: Addison-Wesley.
- Watson, M. (1992). Breast cancer--Is there a psychological risk factor in disease progression? In H. J. Schmoll, U. Tewes, & N. Plotnikoff (Eds.), Psychoneuro-

immunology: Interactions between brain, nervous system, behavior, endocrine and immune system (pp. 259-265). Lewiston, NY: Hogrefe & Huber.

Waxler-Morrison, N., Hislop, T. G., Mears, B., & Kan, L. (1991). Effects of social relationships on survival for women with breast cancer: A prospective study. Social Science and Medicine, 33, 177-183.

Werner, O., & Schoepfle, G. M. (1987). Systematic field work: Foundations of ethnography and interviewing (Vol.1). Newbury Park, CA: Sage.

Wilber, T.K. (1988). Attitudes and cancer: What kind of help really helps? Journal of Transpersonal Psychology, 20, 49-59.

Williams, P. (1993). That other place: A personal account of breast cancer. Toronto, ON: Dunburn Press.

Wittman, J. (1993). Breast cancer journal: A century of petals. Golden, CO: Fulcrum.

White, M., & Epston, D. (1990). Narrative means to therapeutic ends. New York: W. W. Norton.

White, R. W. (1974). Strategies of adaption:An attempt at systematic description. In G. V. Coelho, D. A. Hamburg, and J.E. Adams (Eds.), Coping and Adaptation, New York: Basic Books.

Wood, P. E., Milligan, M., Christ, D., & Liff, D. (1978). Group counselling for cancer patients in a community hospital. Psychosomatics, 19, 555-561.

Woods, N. F., Lewis, F.M., & Ellison, E. S. (1989). Living with cancer: Family experiences. Cancer Nursing, 12, 28-33.

Wool, M. S., & Goldberg, R. J. (1986). Assessment of denial in cancer patients: Implications for intervention. Journal of Psychosocial Oncology, 4, 1-14.

Appendix A

Envelope from British Columbia Cancer Agency

BCCA
1900 Fort Street
Victoria, B.C., Canada
V8R 1J8

Appendix B

Advertisement for Subjects

BREAST CANCER RESEARCH

WOMEN WITH BREAST CANCER: AN ETHNOGRAPHIC STUDY,

BY ALICIA DUNLOP, PH.D. CANDIDATE,

UNIVERSITY OF VICTORIA

WOMEN WHO ARE CURRENTLY DIAGNOSED WITH BREAST CANCER ARE INVITED TO BE PARTICIPANTS IN A DOCTORAL RESEARCH PROJECT AT THE UNIVERSITY OF VICTORIA. THE PURPOSE OF THIS RESEARCH IS FOR THOSE WHO ARE LIVING WITH THE EXPERIENCE OF BREAST CANCER TO SHARE THEIR EXPERTISE AND TEACH OTHERS WHAT THE EXPERIENCE IS LIKE. THIRTEEN WOMEN WHO HAVE A DIAGNOSIS OF BREAST CANCER WILL BE INVITED FOR TWO INTERVIEWS. PRIVACY, CONFIDENTIALITY AND ANONYMITY ARE GUARANTEED. THE RESEARCH PROCESS CAN BE CANCELLED OR CHANGED BY THE INTERVIEWEE AT ANY TIME.

IF YOU OR A FRIEND ARE INTERESTED IN FINDING OUT MORE ABOUT THIS RESEARCH PLEASE CALL:

ALICIA DUNLOP at

UNIVERSITY OF VICTORIA, _____ OR

RESIDENCE, _____.

Appendix C

Letter of Consent

I hereby give my consent for my participation in the study entitled:

Women Breast Cancer: An Ethnographic Study.

I understand that the persons responsible for this study are Dr. Vance Peavy and Alicia Dunlop, University of Victoria, Psychological Foundations, Department of Education, telephone numbers, _____ and _____.

Alicia Dunlop has explained to me that this study has the following objective: to understand what it means to be living in the world of one who has been diagnosed with breast cancer--what this experience is like from each individual participant's perspective.

It is hoped that the findings of this study will offer new insights for counsellors, educators, nurses, social workers, doctors, and volunteers who are working with breast cancer patients, as well as offering support and information for those who are newly diagnosed and their families and friends.

Alicia Dunlop has explained to me that she will take notes and tape record any interview she conducts with me. Precautions for confidentiality and anonymity will be taken by encoding each interview tape numerically. The tapes will not be identified by name and will be destroyed after the data analysis is completed. Only the research supervisor and the interviewer will have access to the audiotapes. I am aware that at any time I may withdraw from the study. I may ask to have the recorder stopped at any time. I may also refuse to respond to any

questions during the interview. If I have any questions about the study I can ask Alicia Dunlop at the time of the interview or contact her or Dr. Peavy by telephone _____ or _____.

My signature indicates that I am willing to participate in this study having read the above.

Name _____

Date _____

Appendix D

Glossary of Terms

Research Glossary

Background meaning: cultural, subcultural, family and personal life experiences from birth. Background meaning determines what counts as real for the person. It is a shared, public understanding of what is.

Cognitivism: Refers to the research approach that views each person's knowledge, understanding, intentions, and actions as originating only in the mind.

Concern: A way of being involved in one's own world where people and things matter. It describes a phenomenological relationship in which the world is apprehended directly in terms of its meaning for the self. Concern is the reason people act.

Coping: What people do when personal meanings are disrupted and smooth functioning of life breaks down. The goal of coping is the restoration of meaning. Coping is a series of strategies that individuals choose. Coping is always bounded by the meanings and issues inherent in what counts as stressful to a particular individual.

Culture: Knowledge people acquire to interpret their experience and generate social behaviour (Spradley, 1979).

Discovery: Data collection; working the field; the second field phase of qualitative research that distinguishes it from nonqualitative research.

Domain: A symbolic category that includes other categories--related by at least one aspect of cultural meaning. It is the basic and most important unit used for ethnographic analysis (Spradley, 1979).

Emic: The individual insider's perspective of a culture. The emic view is grounded in language use and expressions .

Ethnographer: Someone who wants to understand the world from your point of view. She wants to know what you know in the way you know it. She wants to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. She says: will you become my teacher and help me understand?

Ethnography: The work of describing a culture in order to understand another way of life from an insider's or native point of view.

Ethnography (holistic): The description and analysis of all or part of a culture or community by describing the beliefs and practices of the group studied and showing how the various parts contribute to the culture as a unified consistent whole (Tesch, 1990, p. 28).

Etic: The outsider; one who is not part of your culture.

Folk term: Symbols used by the informant to represent cultural meaning.

Goal of ethnography: To discover and describe the cultural meaning system that people are using to organize their behaviour and interpret their experience.

Grounded theory: Theory grounded in data collected directly from individuals.

Ethnography offers an excellent strategy for discovering grounded theory.

Identity: (Taylor, 1977, p.125): "The notion of identity refers us to certain evaluations which are essential because they are the indispensable horizon or foundations out of which we reflect and evaluate as persons. To lose this horizon, or not to have found it,

is indeed a terrifying experience of ... loss. This is why we speak of an 'identity crisis' when we have lost our grip on who we are. A self decides and acts out of certain fundamental evaluations." For example, a shift from being healthy to having cancer was, for many clients, a change in identity.

Informant: A native speaker, or person representative of the culture under study, who through the use of native language provides information to the ethnographer.

Interpretation: Clarifying the meaning of a phenomenon.

Interpretive theory: Interpretation based on thick description; does not generalize across cases, but treats each case as a universal singular.

Patient: "the experiences of being a patient" (Mathieson, 1991, p. 63) in the classic sense of the term: being diagnosed with cancer in a certain site. For example, being a patient for many clients was interpreted to mean that they were now under the care of professionals and had lost some degree of control in their lives.

Phenomenology: Emphasis on the process of observation, sometimes to the exclusion of concern for external reality. A philosophical approach based on the study of the thing(s) perceived.

Professional stranger: Refers to the interviewer who has the privilege of obtaining personal information within the context of the interview (Schwartz & Jacobs, 1979).

Qualitative research: 1) research with a non-statistical premise; 2) observation and interaction the target of study on its own home ground: ethnography, field work, naturalistic research, participant observation.

Reliability: The extent to which the same observation procedure in the same context yields the same information. Reliability is the degree to which the finding is independent of accidental circumstances of the research.

Speech Event: A social occasion which is identified by the kind of conversation that takes place. It involves an implicit set of rules of social conduct such as: when to begin, end, pause, ask questions, and how close to stand to one another (Spradley, 1979).

Stigma: Described by clients as a feeling of shame, of being unwanted, untouchable. For example, many clients felt as though they should shrink back from life as a result of having cancer.

Stress: The disruption of meanings, understanding, and smooth functioning so that harm, loss, or challenge are experienced, and sorrow, interpretation, or new skill acquisition is required.

Tacit cultural knowledge: Knowledge about one's culture that is not usually expressed in direct ways. This tacit knowledge is revealed through people's speech, behaviour, and artifacts (Spradley, 1979).

Translation competence: The ability to translate the meanings of one culture into a form that is appropriate to another culture. Every ethnographic description is a translation.

Validity: The quality of fit between an observation and the basis on which it was made.

Validity is the degree to which the finding is interpreted in the correct way according to those being observed.

Apparent validity (face validity): The obviousness of the relationship between an observational procedure and what it is intended to observe.

Cancer Glossary

Adjuvant treatment: Secondary form of treatment that usually follows surgery and involves chemotherapy or radiation therapy.

Advanced breast cancer: Stage of cancer in which the disease has spread from the breast to other body systems by travelling through the lymphatic system or bloodstream.

Aspirate: Fluid withdrawn from a needle from a lump or mass for microscopic examination.

Axilla: The armpit, underarm, which contains the axillary lymph nodes.

Axillary dissection: incision made under the armpit to remove lymph nodes to determine if breast cancer has spread to other parts of the body.

Baseline mammogram: A woman's first mammogram, usually done between the ages of 35 and 40, which doctors then use as a diagnostic tool for evaluating any changes in future mammograms.

Benign: Not cancerous.

Bilateral: Both sides, e.g., affecting both breasts

Biopsy: Removal and microscopic examination of a specimen of tissue from the body, to make a precise diagnosis as to whether it is benign or malignant. Before a biopsy, the suspicious area is marked with needle(s) and sometimes dye. The surgeon is then able to locate and remove the marked areas of tissue, which are then x-rayed to be sure all the suspicious areas have been removed.

Excisional biopsy is the total surgical removal of the tissue to be examined.

Incisional biopsy is the surgical removal of only a sample of the tissue to be examined.

Needle localization biopsy is a method used when a breast abnormality can be seen on a mammogram but cannot be felt.

Breast reconstruction: The creation or rebuilding of a new breast by plastic surgery, using tissue expanders, silicone implants, or tissue transplants. The surgery can be performed any time, from immediately following the mastectomy to months or years later.

Breast self-examination (BSE): Monthly examination of the breast performed by a woman in which she become familiar with the normal look and feel of her breasts.

Calcification: Deposits of calcium in a breast lump that show up on a mammogram as white dots.

Carcinoma: A general term used to described several hundred different diseases characterized by uncontrolled abnormal cell growth. Cancer cells invade and destroy normal cells and then spread and metastasize to other areas of the body.

Chemotherapy (Chemo): Breast cancer treatment using anti-cancer drugs which have the ability to find and destroy cancer cells anywhere in the body, with side effects such as nausea, hair loss, increased risk of infection, and possible damage to the bone marrow. It is often given in conjunction with radiation and breast cancer surgery. Chemotherapy is said to delay relapse by 30% and lowers the risk of death by up to 25%. The most common drugs used to treat breast cancer are: Andriamycin, methotrexate, 5-fluoro uracil, cyclophosphamide (Cytosan), vincristine, and prenisone.

Cyst: A benign, fluid-filled lump

Cytology: Examining cells from a lump or cyst for any evidence of cancer, as in fine-needle aspiration cytology

Early stage breast cancer/in situ/localized breast cancer: When cancer is limited to the breast and has not spread to the lymph nodes or other parts of the body.

Edema: Swelling or puffiness as a result of retention of abnormal amount of fluid.

Fibroadenoma: A harmless lump formed during the natural growth cycle of a breast lobule

Granuloma: A small lump resulting from chronic inflammation

Histology: The study of tissues under a microscope. The tissues comes from a biopsy specimen

Hormone: A chemical messenger from one part of the body that circulates in the bloodstream and exerts an effect on another part

Hormone therapy: Manipulation of hormone levels in the body that can cause a tumour to stabilize or shrink. Tamoxifan is a common anti-estrogen drug used in the treatment of breast cancer

Impalpable: Cannot be felt

In situ cancer: Noninvasive cancer confined to where it arises. It does not spread and is not fatal

Lesion: Any newly formed abnormal structure in the body

Lobule: The glandular part of the breast where milk is produced

Lump: Mass of tissue found in the breast or other parts of the body; 80% of breast lumps are benign

Lumpectomy: The breast lump is removed with a 1-cm margin of healthy tissue. The axillary nodes are often removed

Lymph nodes or glands: The junctions of the lymphatic system that become enlarged if fighting an infection or cancer

Lymph edema swelling: Chronic edema of the arm due to the accumulation of fluid, as a result of breast surgery, such as axillary dissection and mastectomy. Pain, and stiffness of the arm and hand, due to interference with the lymphatic drainage of the axilla following surgery and more often radiotherapy. Characterized by swelling or puffiness of the arm next to the surgical site.

Lymph node: Bean-sized structures in the lymphatic system that filter cancer cells and harmful bacteria through the lymph fluid, keeping them from entering the blood stream. Their work helps the immune system fight off infection and disease.

Lymph node surgery: Incision made under the armpit to remove lymph nodes to determine if breast cancer has spread to other parts of the body

Malignant: Cancerous

Mammogram: A low-dose x-ray procedure that shows the details of the structure of the breast tissue and is designed to pick up small abnormalities not palpable

Mammography: Process of taking low-dose x-ray pictures of the breast. Screening mammography is for women who have no symptoms; diagnostic mammography is for women who have suspicious breast problems

Mastectomy/Simple Mastectomy: Surgical removal of the breast

Menopause: Cessation of menstruation, usually a normal aging process. It may also occur as a result of chemotherapy, radiation, or hormone therapy (temporarily or permanently)

Metastasis: Spread of a cancer to a distant part of the body where it forms a secondary tumour. It can spread through the lymphatic system, the bloodstream, or across body cavities.

Micro calcifications: Minute calcium deposits that have a white speckled appearance on mammography

Micro metastasis: A secondary tumour formed from only one or two cells that have escaped from the primary tumour

Modified Radical Mastectomy: All of the breast tissue and muscle and most of the axillary lymph nodes removed surgically from behind the breast and under the arm. This is the most common surgery done for the treatment of breast cancer

Needle Aspiration: A diagnostic method of removing fluid or tissue from a breast tumour or cyst by a fine needle for microscopic examination. A special needle can be used to withdraw a piece of tissue or several cells from a solid lump

Negative Nodes: Lymph nodes which are free of detected cancer cells

Oncologist: A physician who specializes in cancer. There are medical, surgical, and radiation oncologists

One-step procedure (one stage): Surgery which does both breast biopsy and mastectomy in one operation

Oncology: The study of tumours

Partial Mastectomy: The lump is removed with a large amount of surrounding tissue when the cancer does not have a distinct outline. The axillary lymph nodes are also sampled or cleared

Peau d'orange (literally “orange peel skin”): Dimpling of the skin caused by a breast tumour spreading upwards attached to the skin

Positive Nodes: Lymph nodes which have been invaded by cancer cells

Prosthesis: An artificial or replacement body part

Quadrantectomy: An operation that removes a quarter of the breast

Radiation Therapy: Treatment of breast cancer by x-rays or high-dose radiation to reduce or eliminate malignant cells. Frequently used after a lumpectomy

Radiologist: A specialist who takes and reads x-rays

Radiotherapist: A specialist who gives radiotherapy

Recurrence: Return of cancer at the same site equals local recurrence; near the first site equals regional; or in other areas of the body equals metastases

Side effects: Reactions of radiation treatments or chemotherapy which are usually temporary, such as nausea, hair loss, vomiting, or weight gain

Simple/total mastectomy: All of the breast tissue is removed, including the nipple and aureole. no muscles are removed. The axillary lymph nodes may be sampled or cleared

Stage I or Stage T1: The best prognosis. It is early stage, in situ, or localized, and means the cancer appears to be only in the primary site

Stage 2 and 3: Regional breast cancer means the cancer has spread to nearby lymph nodes or other tissues

Stage 4: Distance stage which indicates that cancer has spread to other part of the body

Staging: A system for classifying breast cancer for its stage of development and spread, as diagnosed through x-rays, blood tests, body and bone scans. In breast cancer diagnosis, these tests are done after the biopsy or mastectomy to determine the level of malignancy. The stage of breast cancer will determine the treatment

Tumour: A new lump which can be benign or malignant. It is a growth of cells in which the multiplication of cells is uncontrolled and progressive

Two-step procedure: Breast biopsy and breast surgery performed in two steps which allows for the diagnosis and treatment to be separated by hours, days, or longer

Wide excision: Cutting out a lump with a minimum of 1-cm of tissue around it

Appendix E

Universal Semantic Relationships

Spradley (1979) defines the following as universal semantic relationships:

- | | |
|------------------------|--|
| 1) Strict inclusion | x is a kind of y |
| 2) Spatial | x is a place in y
x is a part of y |
| 3) Cause-effect | x is a result of y
x is a cause of y |
| 4) Rationale | x is a reason for doing y |
| 5) Location for action | x is a place for doing y |
| 6) Function | x is used for y |
| 7) Means-end | x is a way to do y
x is a stage in y |
| 8) Sequence | x is a step in y
x is a stage in y |
| 9) Attribution | x is an attribute of y
x is a characteristic of y |

Appendix F
Demographics

Informant	Age	Background	Religion	Education	Job	Marital
Yolande	63	Canadian	United Church	B.A.	Retired Personnel	Divorced
Sharon	58	Canadian	R.C.	11 Gr	Housewife	Married
Margaret	67	Slavic	Greek Orthodox	CGEP	Retired Bookkeeper	Married
Carol	48	Scottish	Presbyterian	R.N	Health Manager	Single
Anne Marie	56	British	Anglican	R.D.N.	Reg. Dietitian	Divorced
Susan Harris	46	American	-	Ph.D.	Professor	Single
Denise Forest	51	American	Dao	M.A.	Teacher	Divorced Lesbian
Elaine Zyri	48	Slavic	-	R.N.	Nurse	Divorced
Donna	60	British	Anglican	College	Secretary	Single
Vera	86	Canadian	United	-	Retired House-keeper	Widowed
Jane	41	New Zealand	United	M.D.	Doctor	Married
Laura	52	Caribbean	Protestant	-	House-keeper	Single
Rose	75	Poland	Judaism	-	House-keeper	Widowed