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Cancer Experiences of Urban American Indian Women: A Narrative Approach

by

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in

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Fall 1998
The thesis of Virginia Kathleen Mommsen is approved:

Chair  

Date  

Date  

Date  

University of California, Berkeley

Fall 1998
Dedicated to the women participants of this project who
graciously allowed me into their lives, and generously
gave of their time, their thoughts, and their stories;
to others who have suffered in silence.
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Chapter One: Introduction

Currently, the greater San Francisco Bay Area has the third largest urban concentration of American Indians in the United States, after Los Angeles, California and Tulsa, Oklahoma. The 1990 census reports that there are now more than 40,000 American Indian people living in the Bay Area, and many believe this statistic to be a gross underestimate (Community Mobilization Project, 1996, p. 9). Nonetheless, it is widely recognized that the American Indian population in the greater Bay Area has increased over 600 percent since 1960. This phenomenal growth rate has been primarily due to relocation programs that brought American Indian people to the area--Oakland, San Francisco, and San Jose--between 1950 and 1970. However, the migration of rural native California Indians to urban areas has contributed as well. There has been little attention focused on the adjustment of this population of American Indians to urban life. The available information tells of the extreme challenge involved in the adjustment. Severe difficulties in adapting to urban life originated in part from the intrinsic structure of the federal relocation programs. The programs were designed to promote maximum and rapid "assimilation" into the dominant American culture. To this end, relocated people of the same tribe were moved to multiple distinct areas throughout one region, or sent to entirely different cities if possible. This prevented the formation of neighborhoods of American Indian people, and created a minority group with very little political power (Fixico, 1986, p. 134-157).

The health of American Indians in the Bay Area has been tenuous since the beginning of their urban migration. In addition to the fact that relocation programs failed to provide sufficient support in terms of employment and
housing, many relocatees suffered tremendously upon the confrontation with the urban culture that was wholly unlike reservation culture, and largely oblivious to Indian culture in general. For many, relocation led to economic crisis and dissolution of former family and social ties. The large scale result of this was the creation of a distinct disenfranchised underclass of urban Indians. Not surprisingly, securing adequate medical care was one of many difficulties for this group. This problem has remained, and today a large proportion of urban Indian people are uninsured. One study estimated that one-third of California Indians had no health insurance (Community Mobilization Project, 1996, p. 12). In recent years, several community-based organizations and human service agencies have attempted to address these problems. These groups have provided many needed services, as well as stimulated a sense of community among the urban Indian population.

However, difficulties remain. The rate of unemployment among urban Indians is extremely high. There are some estimates as high as 36 percent—as opposed to 5 percent for the general population (Community Mobilization Project, 1996, p. 11). Not surprisingly there is a disproportionate number of Bay Area urban Indians living below the poverty level. The Coro Foundation found a poverty rate around 26 percent in 1988, compared to approximately 9 percent of non-Indians (Community Mobilization Project, 1996, p. 11). These socioeconomic factors are intimately related to the health status of the urban American Indian population.

Clearly then, an urban American Indian individual confronted by a life-threatening illness, such as cancer, is often in dire circumstances. The needs and experiences of individuals in these circumstances are poorly documented, if documented at all. This project explores the experiences of a group of
individuals in this category—urban American Indian women living with cancer.

Three years ago, I began searching for a thesis topic relating to urban American Indian women’s health for several reasons. The first was a fundamental personal interest in becoming more aware of the current health status of today’s American Indian people. In my own experience of three years of medical education, to date, this topic has never been mentioned. Second, upon taking a course titled Urban American Indians, I was surprised to find out that currently over 70 percent of American Indians in the United States reside in cities. This led me to question how these urban-dwellers fared in the acquisition of health care services. I chose to focus on women because women’s stories have been so frequently neglected, and because of my commitment to women’s health. Women’s health and Indian health, and most certainly Indian women’s health, are topics that have generated shockingly small amounts of literature until very recently. Even now, many people feel that these topics are not given the attention they demand, and that the methods used to address them are insufficient.

The idea for this project was to examine a health issue for American Indian women from a feminist perspective, through a qualitative method of analysis. The aim of this research design was to preserve the voice, or the flesh, of the women’s stories, and elucidate issues truly salient to them and their health.

The project was originally conceived to focus on women who had experienced cervical cancer. This focus emerged out of several anecdotal stories that seemed to correlate with epidemiologic literature. The literature reports that American Indian women have cervical cancer mortality rates substantially higher—most studies reporting two to as great as four times higher-
-than all other American ethnic groups (Dignan, 1993, p. 279-280). This is not due exclusively to late diagnosis or high incidence, although both of these are significant contributors.

The anecdotal stories were told to me by several local Indian women, and were about women they had known with cervical cancer. These women were their mothers, grandmothers, friends, or friend's mothers, who had died of metastasized cervical cancer. In each case, no one knew that the woman had cancer until she died. Some of these women refused to go back for treatment after their diagnosis, and most never spoke to anyone about their illness. I found these stories disturbing. They inspired me to focus on women with cervical cancer, and to design the project with the women's words at its core.

Due to difficulties in recruiting a sufficient number of women with cervical cancer, which will be discussed in Chapter Three, the project was expanded to include women with other cancers as well. This did not change the fundamental goal of the project. The goal was to document the women's experiences with cancer in their own words, and note patterns in their stories. Specifically, two major research questions emerged: (1) What have been the experiences of urban American Indian women with cancer? and (2) What did these women need during the time of their illness?

The following document represents my effort in seeking preliminary answers to these questions. Chapter Two is a review of the relevant literature on the topic of cancer among urban American Indian women. Chapter Three presents the theoretical perspective, research design, and execution of this project. Chapter Four introduces the women participating in the project and Chapter Five presents the major findings elicited from the analysis of the women's stories. Chapter Six summarizes the project and discusses
implications of the findings as well as directions for future research.
Chapter Two: Background Literature

For several reasons, reviewing the literature on the experience of urban American Indians with cancer is quite challenging. First, there is very little literature that deals specifically with the health status of urban American Indians as opposed to those living in rural or reservation areas. Secondly, accurate cancer rates in Indian populations are often very difficult to calculate. For example, cancer incidence rates in the Oklahoma-Kansas area, California area, and Portland area (Washington, Oregon, Idaho) are inaccurate because of problems with reporting of race on death certificates. These inaccuracies are so pronounced that, although these areas have large populations of American Indian people, they are excluded from national statistics (Hampton, 1993, p. 243). One study of Portland area American Indians found that only 60 percent of patients registered with the Indian Health Service, and for whom race was recorded, were identified as Native Americans in the Surveillance Epidemiology and End Results (SEER) cancer registry (Frost, 1992, p. 957). An older study in the same area reported that one third of the infants recorded as being Native American on their birth certificates were not recorded as Native Americans on their death certificates. Problems such as this are undoubtedly amplified in urban areas where identities of American Indians are rarely as clear as in reservation settings.

In 1990, the Network for Cancer Prevention and Control (a network established between the National Cancer Institute and the Indian Health Service) set up subcommittees to assess racial misclassification of American Indians and Alaska Natives. These subcommittees found extensive underreporting of cancer in urban populations due to racial misclassification.
The Network suggested education for researchers and providers about underreporting as a growing public health problem, and more funding for health care and research on cancer in American Indians (Hampton, 1993, p. 244).

Another reason the health status of urban populations is difficult to assess is that urban peoples often obtain their health services from variable or multiple sources. This is very different from the contained reservation setting where the Indian Health Service is in charge of health services for all residents. This is not to say that reservation records are infallible, but they are definitely more accessible than those in urban clinics where patients are often seen at random intervals, and frequently only in emergencies. These circumstances make accurate or comprehensive medical records nearly impossible to obtain. In addition, cultural forces within the urban American Indian community may contribute to underreporting, and thus inaccurate records. This issue has not yet been systematically explored.

**General Cancer Trends among American Indians**

Despite the stated complications in obtaining cancer statistics among American Indians, and urban dwellers specifically, some important trends have emerged in the literature that are worthy of mention. First, cancer has been found to be the second leading cause of death in American Indian women, and the third leading cause in American Indian men (Joe, 1993, p. 239). Cancer is second following heart disease for women, and heart disease and accidents for men (Dignan, 1993, p. 279). This information is limited, however, as research has been conducted on only a few of the 510 recognized tribes. In a search by one researcher compiled for the years 1800-1989, only 84 articles were found in which cancer in American Indian populations was the primary subject (Joe,
Recently, however, quantitative health data on American Indians has been accumulating. These data suggest that the health status of American Indians has been improving, but remains far behind that of the U.S. general population (Dignan, 1993, p. 279). In terms of cancer, notable variations from tribe to tribe in site-specific cancers are emerging. Childhood cancer appears to be lower for American Indians and Alaska Natives, but many other cancers appear to be increasing, and survival rates, sadly, remain extremely poor for virtually all American Indians and Alaska Natives (Joe, 1993, p. 241). Several studies have shown that excesses in mortality exceed those of incidence rates. Low survival rates may be due to more virulent disease, genetic predispositions, late stage diagnoses, "less than optimal treatment," or "poor outcome due to other unidentified factors" (Lanier, 1993, p. 245-246). Potential reasons for late diagnosis, further explanation of "less than optimal treatment," and further exploration of "unidentified factors," are issues that will require in-depth attention if they are to be understood more thoroughly in the future.

Although patterns of cancer occurrences in American Indians are distinct, current literature reports low overall cancer rates. These rates appear to be approximately one-half to two-thirds the national rates overall for non-Indians. However, as stated earlier, the extent to which these rates are due to inaccurate reporting of race is unclear. Even if cancer rates are truly low overall for American Indians, this does not eradicate the need for cancer prevention in American Indian populations. One reason for this is that certain cancers are extremely prevalent and lethal in American Indian populations. A second reason is that cancer in American Indian and Alaskan Natives may be on the rise due to increasing life expectancy. Currently death rates among 25-44 year
old American Indians are approximately double that of non-Indians. As premature deaths from causes such as accidents, homicide, and suicide decrease in the American Indian population, life expectancy is predicted to increase. Accompanying this increase may be a rise in cancer incidence and mortality due to a greater proportion of the population living to an older age (Holden, 1990).

Further concern was raised by a recent study on avoidable mortality risks and cultural identification among urban American Indian youths. This study found that for American Indian youths living in New York City with a higher degree of cultural identification—those who self-identified as more closely following the “American Indian way of life”—had some degree of protection against diet-related cancers (Holden, 1992, p. 288). As new generations of urban American Indians become increasingly assimilated into “mainstream” American culture, cancer rates could rise to the level of that culture as well.

**Cancer in American Indian Women**

In 1891, an article published in a journal of the American Gynecological Society stated that "malignant diseases of the reproductive organs seem almost unknown among Indian women" (Hampton, 1993, p. 243). Statements such as these have led many people to believe that cancer in Indian women is a new problem. Data supporting or contradicting this historic assumption have not been found. Regardless, cancer now affects many American Indian women, some of whom still believe that cancer is a "white man's disease." In many circles the problem of cancer in American Indian women goes largely unrecognized. Misconceptions about Indian women and cancer exist among health care providers, clinical researchers, private cancer societies,
foundations, and many women themselves (Hampton, 1993, p. 243). It was reported to me by a researcher at the Center for American Indian Research and Education (CAIRE), that the medical director of one of the Bay Area Indian clinics, who was hired by CAIRE to do a presentation for Indian women on cancer screening procedures, "got up in front of the women and told them that it was 'bullshit' that they needed to get mammograms because Indian women don't get breast cancer." Clearly, the idea that cancer does not affect Indian women is coming from many different levels in society. In the process of researching this project, four women in the Bay Area that had been diagnosed with breast cancer were interviewed. I was told by health care workers at the clinics about several others. The idea that Indian women don't get breast cancer is a dangerous misconception.

Although there is currently no epidemiologic data available for northern California, breast cancer incidence in American Indian women from other areas has been reported to vary from 20 percent to 70 percent of the rate in the overall U.S. population (Nutting, 1994, p. 1631). Cervical cancer incidence and mortality rates among American Indian women are now well documented as being at least double that of non-Indian women in the U.S. (Dignan, 1993; Becker, 1993; Band, 1992; Buckley, 1992) Elevated incidence rates of cervical cancer have been reported among American Indian women in the Washington area (Sugarman, 1994, p. 440), in the Southwest (Becker, 1993, p. 255), in New Mexico (Becker, 1992, p. 376), in Alaska (Lanier, 1993, p. 245), and among native Indian women in British Colombia (Band, 1992, p. 1802). Some areas, such as the Nashville, Tennessee area, report rates four times greater than that of all other racial/ethnic groups. Even though American Indian women constitute a very heterogeneous group, consistency in patterns of cervical
cancer have been observed (Mahoney, 1992, p. 432).

This high rate of mortality from cervical cancer among American Indian women is particularly disturbing in light of the fact that cervical cancer is one of the few cancers that, if detected at an early stage, can be treated successfully in nearly all cases. It is well established that widespread cervical screening results in diagnosis at an earlier stage of disease, and that this is related to reduced mortality (Mahoney, 1992, p. 432). The exact cause of the increased incidence and mortality of cervical cancer in American Indian women is unclear at this time. Several risk factors may be contributing to high incidence and mortality rates. Although a discussion of all potential risk factors is beyond the scope of this paper, a brief examination of utilization patterns of medical services is relevant. A recent study of cervical cancer screening in urban and rural Canada documented that Canadian Native women utilized available screening programs to a significantly lesser extent than other women (Hislop, 1994, pp. 29-31). Another study of urban and rural American Indian women in the Pacific Northwest documented that the higher mortality rates could be due to the failure to screen high-risk women. This study also noted that screening rates and adherence to follow-up could be possible factors contributing to increased mortality, and that these factors need to be further characterized in the population studied (Gilbert, 1995, pp. 183-185). In New Mexico a study has recently shown that after state public health agencies and the IHS promoted screening for the early detection of cervical cancer among minority women, the incidence of invasive cervical cancer for American Indian women was dramatically decreased. In fact, the study found that incidence of the invasive cancer was related inversely to the proportion of the population screened (Chao, 1996, pp. 205-206). All of these studies suggest that the failure of
screening programs has at least partially affected the mortality rates of both
urban and rural Indian women. Reasons for this need to be explored, and
programs targeted appropriately towards this simple and potentially life-saving
intervention need to be developed.

In this study, potential reasons for the failure of screening programs, as
well as under-utilization of services in general, and other factors that may lead
to late-stage diagnosis and high morbidity, are explored through the personal
narratives of women. The narratives are approached with a specific theoretical
perspective. That perspective is described in the following section.

Theoretical Perspective

As previously stated, it was my goal to design this project with the
women's actual words as the main substance of the final product. To this end, it
seemed logical to collect data in the form of oral histories. This goal and design
materialized largely due to my interest in approaching the project from a
feminist perspective. In the following quotation, the Personal Narratives Group
describes the relationship between "feminist theory," and using personal
narratives to better understand the lives of women:

Feminist theory emerges from and responds to the lives of women. The recovery
and interpretation of women's lives have been central concerns of feminist schol-
arship from the earliest pioneering works to the present. Listening to women's
voices, studying women's writings, and learning from women's experiences have
been crucial to the feminist reconstruction of our understanding of the world.
Since feminist theory is grounded in women's lives and aims to analyze the role
and meaning of gender in those lives and in society, women's personal narratives
are essential primary documents for feminist research (1989, p. 4).

There is some controversy over what the "aims" of "feminist research" ought to
be, and whether or not "feminist methods" actually exist. Although that
discussion is beyond the scope of this paper it is important to note that this
project was approached from a feminist perspective, as described in the follow-
ing passages. The idea of feminism as a perspective has been discussed extensively by Shulamit Reinharz:

The materials covered in the preceding chapters suggest that feminist researchers do not consider feminism to be a method. Rather they consider it to be a perspective on an existing method in a given field of inquiry or a perspective that can be used to develop an innovative method. The fact that there are multiple definitions of feminism means that there are multiple feminist perspectives on social research methods. One shared radical tenet underlying feminist research is that women's lives are important. Feminist researchers do not cynically "put" women into their scholarship so as to avoid appearing sexist (1992, p. 241).

For this project I have chosen to use personal, loosely-structured interviews as the main source of data. This method was an attempt to let the women speak for themselves. As Dorothy Smith has noted:

Our training teaches us to ignore the uneasiness at the junctures where transitional work is done--for example, the ordinary problems respondents have of fitting their experience of the world to the questions in the interview schedule. It is this exclusion which the sociologist who is a woman cannot so easily preserve, for she discovers, if she will, precisely that uneasiness in her relation to her discipline as a whole (1974, p. 93).

I tried to dissipate some of my personal uneasiness regarding the issue of fitting real life experiences into an interview schedule by using the less structured interview format. As suggested by Anderson and Jack:

If our questions are general enough, women will be able to reflect upon their experiences and choose for themselves which experiences and feelings are central to their sense of their past (1991, p. 17).

It is unclear whether or not the interviews conducted for this project were entirely successful in achieving this end, but having the women "choose for themselves" which experiences and feelings were of central importance was most certainly the goal. The interview continues to evolve as a tool in social science:

The interview is a critical tool for developing new frameworks and theories based on women's lives and women's formulations. But we are at an awkward stage: old theories are set aside or under suspicion and new ones are still emerging. We must therefore be especially attentive to the influences that shape what we hear
and how we interpret. How do we listen to an interview when we have rejected the old frameworks for interpretation and are in the process of developing new ones? How can an interview pull us beyond existing frameworks so that we stretch and expand them? (Anderson and Jack, 1991, p. 18).

There is one more aspect of the feminist perspective expressed through this research that is worthy of mention here. Reinharz discusses the notion of the involvement of the researcher as a person:

...feminist researchers generally consider personal experiences to be a valuable asset for feminist research. To the extent that this is not the case in mainstream research, utilizing the researcher's personal experiences is a distinguishing feature of feminist research. Personal experience typically is irrelevant in mainstream research, or is thought to contaminate a project's objectivity. In feminist research, by contrast, it is relevant and repairs the project's pseudo-objectivity. Whereas feminist researchers frequently present their research in their own voice, researchers publishing in mainstream journals typically are forbidden to use the first person singular voice (1992, p. 258).

The idea for this project was sparked by stories that touched me personally. Moreover, the approach to the questions in the study is one that is personally appealing to me. In the following chapter, which describes the research design and execution of the project, I will discuss some of the biases that, as the researcher, I may have brought to this project. It should also be noted that the data collected for this project were rich, and I have approached them in only one of many possible ways.
Chapter Three: Methods

To the best of my knowledge, there has never been a published qualitative study exploring American Indian women's subjective experience of cancer. Although quantitative data on Indian women's health status is accumulating, as is some amount of biomedical research, no one has to date explored the issue of cancer in Indian women from the women's point of view. This paper aims to begin that process.

By approaching this problem in a qualitative way, further information can be obtained on why women underutilize services and in what ways they may be receiving less than optimal health care. In addition, new ideas regarding "unidentified factors" contributing to increased mortality rates may emerge. The exact methods used in this study are described in the following sections.

Data Collection

Data were collected by interviewing eight women at length about their experiences with cancer. The women were recruited by fliers posted at various American Indian organizations in Northern California, as well as by fliers handed out by community health care workers at the same organizations. The women then called me directly to schedule an interview or gave their name and number to the health care worker who gave the information to me. I then called the women to schedule an interview. The interviews lasted between forty-five minutes to two and a half hours, with a median length of approximately one hour. Each woman was given a nominal monetary compensation of twenty dollars for her participation.

Six of the interviews were held at the homes of the women, one was held
in an upper loft room of the woman's church, and one was conducted by telephone. All of the interviews were tape recorded, and then transcribed, except for the telephone interview. The telephone interview was recorded by manual note taking, and then transcribed by me immediately afterwards. Due to a tape malfunction, one-half of one interview was not recorded. This material was reconstructed by me through manual notes and memory. In my judgment, there was no significant loss of data stemming from this reconstruction.

The interviews were primarily open-ended, beginning with a statement by the interviewer such as, "You can start by just telling me what happened when you were diagnosed with cancer." Following this statement, questions were asked following-up issues introduced by the interviewee, as well as some questions predetermined by the interviewer to be used if necessary (see Appendix A). Questions were also asked in reference to issues brought up by women in previous interviews. Clearly, not all interviews covered precisely the same ground. This was intentional by the design of the study, with the hope that each interviewee would be able to discuss in-depth the issues most important to her. In other words, this open-format was used so that the women could create the agenda, and be less enticed into the agenda of the interviewer.

In order to maintain the confidentiality of the participants, all of their names, as well as the names of other individuals they mention, have been changed in the following text, as well as in the original transcripts. The last names of the participants were not collected at all, to further insure confidentiality. The key to the participants real and changed first names is kept locked in a safe place.
**Data Analysis**

All of the interviews were transcribed by me personally, except for one, which was done by a local transcription agency. Following and during the transcription, general themes in the interviews, such as the discussion of "interactions with providers," "reaction to diagnosis," and "concern for children" were noted. Separate lists of general topics such as these were created by me several times by assigning a code in the margin of the transcript where the woman discussed the particular topic. By listing the codes from all of the interviews, and then further coding the transcripts with more precise codes such as "negative interaction with provider due to miscommunication," or "need to maintain hope after diagnosis," and then going back again to other women's interviews, looking for similar topics, the final categories began to emerge. These "final" categories were collated again, and analyzed for similarities or existing themes. Throughout this process, computer files were created for different categories, and relevant quotations were copied into those files. Through this "grounded" method, that involved the original transcripts at all times, patterns in the women's experiences gradually emerged. These patterns are presented in Chapter Five as the major findings of this study.

**Difficulties**

The main difficulty with this project was the initially low response rate. As mentioned previously, due to the lack of sufficient response from women with cervical cancer, the project was expanded to include women with other cancers. There are several possible reasons for this lack of response. First, although the epidemiologic data show high rates of cervical cancer in urban and reservation American Indian women, several of the Native American Health Centers that became involved in this project, reported very low rates of cervical cancer. The
reported low rates could be due to the fact that the existing epidemiologic data
does not cover urban areas in northern California, and that the high rates of
cervical cancer found elsewhere are not found in this area.

The discrepancy may also be due, as some health care workers at the
clinics thought, to the fact that since the problem of cervical cancer has become
so widely recognized, women and health care providers are becoming more
aware of potential risk factors, and thereby are decreasing incidence. One
nurse mentioned that, although they “have not seen a case in three years, this is
one of [their] highest priorities at the center, and practically every woman who
walks through the door gets a Pap smear.”

On the other hand, women with cervical cancer could simply not be
seeking treatment, which is not an unlikely possibility. The decision not to seek
treatment would probably preclude a woman from seeing a flier posted at a
health center as well as indicate that she would not be interested in participat-
ing in a project such as this one.

Another possibility, raised by an Indian woman not affiliated with the
clinics, was that most women are not going to the Native American Clinics to get
their Pap smears. This woman explained that she would not go to the Native
American Clinic for a Pap smear due to fears related to confidentiality, as well
as overall competency and cleanliness. Her belief was that women probably go
to facilities other than the Native American Clinics if they have the choice. The
problem of confidentiality was also raised by several health workers from the
clinics, as an element of care that they were working to improve. Additionally,
some women undoubtedly go to other facilities because their insurance
dictates. Gaining a better understanding of this issue is beyond the scope of
this project, but may be very important for future research.
Potential Bias

The preceding difficulties also bring up some of the major selection biases of this project. Namely, seven of the eight women participating were receiving services from one of four Native American Clinics in the area. This means that they were in fact receiving treatment for their condition. Women who were not actively involved in pursuing health care were less likely to become involved in this study. This selection bias could produce results significantly different from those that may be produced by a study including women who chose not to seek medical care.

In addition, probably because the main source of recruitment was through these clinics, the sample in this project consists mainly of women who do not have insurance through a job, a spouse, or some other outside source. The women in this project depended primarily on government assistance programs. This selection bias produces a particular slant to the research that, in some ways, is very useful. Information concerning low-income or underserved populations is often difficult to obtain.

An important limitation of this study is that even with the expanded participant category the sample size remains small. Generalizations to a larger population, therefore, cannot be made. However, due to the qualitative nature of the study, much information can be elicited from the relatively few participants. Although this information defies generalization, it is extremely revealing of important contextual points that lend themselves to further study in larger groups.

Another potential bias of this study, is that I, the principal investigator, am a white, health care provider in-training, and the women participants in the
study are American Indian, as well as patients in the world of health care. In the context of twentieth-century America, this arrangement introduces the possibility of much potential bias. The unfortunate historical relationship between whites and Indians in this country is still our collective legacy, and consciously or unconsciously part of our collective mind. The tainted history of the medical profession toward American Indian people, and the historical relationship between medical providers and patients in general, present additional levels of potential bias. It is my hope that with the concentrated effort to remain closely connected to the words of the women participants, I will be able to move away from these potential biases. I also hope to reveal something that is both “true” to the women in their lives, and potentially helpful to Indian women in the future. I believe that there are planes of existence where the research participants, and I, the researcher, have significant commonalities--mainly in our experience of being women, urban dwellers, and human beings. I believe these commonalities served us well toward achieving the goals of this project.
Chapter Four: The Women

This chapter provides an introduction to the women participants in the project. The first section presents an overview of the demographic characteristics of the women, and the second section provides a brief biographical sketch of each participant. Additional demographic data are presented in Appendix B.

Demographic Summary

Eight women participated in the project. All self-identified as American Indian, and resided in an urban area in northern California. In addition, all had some form of cancer. Four of the women had cervical cancer, one had cervical carcinoma-in-situ\(^1\), four had breast cancer, and one had colon cancer. One woman had both cervical and breast cancer, and one woman had both breast and colon cancer (hence the aforementioned total adds up to ten rather than eight).

The women ranged in age from 38 to 68 years old, with the average age being 52.3 years old. The women’s living situations varied. Two of the women lived alone, two shared houses with husbands from whom they have been separated for many years, one lived with her husband, one lived with her teenage daughter, one lived with her adult daughter, her grandchild and her sister, and one lived with her mother, her grandmother, five of her children, and her two grandchildren.

Seven of the women were unemployed at the time of the interview, although all had worked in the past. One woman worked as an assistant at a

\(^1\) Cervical carcinoma-in-situ is technically a precursor to cancer that will develop into a cancerous lesion if not treated. Although this distinction is important medically, for several reasons, I felt that for the purposes of this project, the distinction was less important. A woman with cervical carcinoma-in-situ is told that she has a 'carcinoma', stage 0, and she is recommended the same surgical treatment as a stage 1 carcinoma.
veterinary clinic, and a pet-sitter. All of the women in the study were "low-income." Six received insurance through Medi-Cal or Medicaid, one received Medicare, and one had private insurance through her employer.

The women self-identified as being Apache, Canadian Indian, Cherokee, Chickasaw, Choctaw and Chickasaw, Quileute, Sioux, and Wylacki, coming originally from several different areas of the country.

**Biographical Sketches**

**Ada**

Ada is a 38-year-old woman who lives in a small house in Sacramento with her mother, her grandmother, five of her six children, and her two grandchildren. Ada was divorced many years ago, and is currently in a relationship with a male partner who she feels is very supportive of her.

Ada is a Wylacki woman who grew up on the Round Valley Reservation in northern California. She left the reservation when she was 22 or 23, and has since lived in Ukiah and Eureka. Several years ago she moved to Sacramento to live with her mother. Before being diagnosed with cervical cancer in 1995, Ada worked in a hospital as an "assistant with head injuries in rehab."

Ada's cancer was quite advanced when she was diagnosed. She feels that she was partly responsible for this because she had not been to the doctor for several years prior to her diagnosis. She had "lost a baby" three years before, and was supposed to go in for a follow-up appointment, but never went due to her distress over losing the baby. To her, "losing the baby was more difficult than the cancer." In addition, other family problems that she experienced during the treatment of her cancer made her cancer "not so much a
big thing," just something she had to "deal with."

Despite the advanced stage on diagnosis, Ada’s treatment has been successful, and her cancer has remitted. She is glad that her family has always been "supportive and loving," and she is now focusing on getting healthy so that she can go back to work in the future.

**Beatrice**

Beatrice is a 68-year-old woman who lives on one floor of a house she shares with her husband (from whom she is separated, and who lives on the other floor) in Union City. Seven of her ten children are still living, and they all live in the area. She does not get much support from her family, and says she doesn’t want it. She likes "to be independent."

Beatrice grew up on Mescalero Reservation in New Mexico, and she is "proud to be an Apache!" Although she left the reservation when she was young, she felt like her strict "upbringing" there influenced many of her attitudes about her cancer. She said it was very difficult for her to admit she was sick, and to show emotion about it.

Beatrice was diagnosed with breast cancer around 1990, which was treated successfully with surgery. In 1993, she was again diagnosed with cancer, this time of the colon. For this cancer, she went through surgery, radiation and chemotherapy. For her, the most difficult part of her experience was going through the chemotherapy. She is now very happy to be reaching her 5-year survival mark.

Beatrice worked for 24 years as the "manager, bartender, and bouncer" of a nightclub. Several years ago, she decided she wanted to get out of the nightclub business, and she is now training to become a special-education
teacher. She is also very active in her church. Beatrice is “very satisfied” with her life right now.

Josie

Josie is a 48-year-old woman who lives in a small apartment with her 18-year-old daughter in West Oakland. She has a sister and a brother that live in the area, but the rest of her family lives “back East.” Her family is originally from the Mississippi area, and they are “Choctaw, Chickasaw and English.” Josie is single, and a single parent to her daughter. Up until her diagnosis with breast cancer, Josie was working as an Instructor’s Assistant for the Oakland School District at the Junior High level.

Josie was diagnosed with breast cancer in 1995, after getting a mammogram from a mobile breast cancer screening van sponsored by two local hospitals. After this, she was referred to the county hospital where she able to get “real fast” care due to a special program that had been set-up for “minority and low-income women.” She was grateful for the treatment she got through this program, and after the long and draining treatment period, her cancer is now in remission.

Josie grew up in Chicago, and moved to Oakland in 1985. Since her relocation she has been very involved in her church community, and in gospel singing. She especially enjoys the singing she does with a Bay Area acting group. Josie suffered a permanently damaging side effect from her chemotherapy, and because of that is now very limited in her activities. She will not be able to go back to work, but she says she is “enjoying life” now, and “reliving her childhood” by doing relaxing things that she has “not done for years” like “arts and crafts with feathers.”
**Lornah**

Lornah is a 54-year-old woman from Oakland who now lives on the Rosebud Reservation in South Dakota. She recently moved from Oakland to the Sioux reservation, where she was born and raised. For financial reasons, as well as other reasons that will become evident in the next chapter, Lornah felt that the reservation offered a more comfortable place than the city of Oakland to spend the remaining years of her life. She now lives with her husband with whom she reunited after a long period of separation. Her three children also now live on the reservation, as well as her 19 grandchildren, and 3 great-grandchildren.

Lornah has had a long journey with cancer. She was first diagnosed with advanced cervical cancer in 1969, which was eventually treated successfully with surgery. In the early 1980's she was diagnosed with breast cancer, which was found to be metastasized by 1985. She has been living for the past 13 years with that cancer. Her story of survival is a very rare and amazing one. At the present time, Lornah travels periodically back to Oakland to receive ‘conventional’ treatments, such as surgeries, but most of her treatment now comes from a traditional medicine man. Lornah remains a very active person who raises chickens, gardens, and is involved in the lives of her family and her community.

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2 Although I initially scheduled an interview with Lornah when she was to be in Oakland, she was unable to make that interview. For this reason, she was interviewed by phone from South Dakota.
Luci is a 50-year-old woman who lives in East Oakland in the home of her husband from whom she has been separated for over 10 years. She has one daughter, and although she lives in the area, she does not see her very often. She is still “friends” with her husband, and thankful that she has been able to live in his house, but would like to move out if she could. She is now trying to become financially stable after a long and difficult period in her life.

Until Luci was about four years old she lived with her mother, who was a Quileute woman, who moved between Oregon, Washington, and California picking fruit, and some vegetables. Her father died when she was very young. At the age of four, she was sent to live with her grandmother due to her mother’s alcoholism. She stayed with her grandmother until she was nine years old, and then she was raised in foster homes until the age of seventeen. Her early life was extremely unstable, but she is very proud of the fact that she managed to graduate from high school with several honors. She has worked as an administrative assistant, a waitress, and a bookkeeper.

Luci first learned she had advanced, “inoperable” cervical cancer in 1982. Her cancer was sufficiently localized, however, that her doctors were able to treat her with radiation. Although it took nearly a year of radiation, her tumor shrunk substantially. At that point, she underwent a 53 hour surgical procedure involving radiation implants, which was able to dissolve the rest of her tumor. Her oncologist told her that she has “never had a patient take that much radiation.” Luci was quite proud of this fact, as well as the fact that through her long treatment period and advanced disease, she served to educate many doctors.

Luci described the “aftermath” following the remission of her first cancer
as the worst part of her entire experience. The anguish she experienced at that
time initiated her into years of drug and alcohol problems that she had never
experienced in the past. These problems did not end until she was diagnosed
with recurrent cervical cancer in 1995, almost ten years later. But this time she
was able to take a different path, and not only make it through the cancer
therapy, but kick her drug and alcohol habits as well. Although her health and
living situations are still frequently tenuous, she is happy to be "50, and doing
real good."

**Mina**

Mina is a 56-year-old woman who lives in Pittsburgh, California in a two-
bedroom house with her sister, her 22-year-old daughter, and her three-year-
old grandson. They are the only family that she is currently in contact with. She
was abandoned by her first husband over 25 years ago, and the three children
that she had from that marriage were stolen from her by her next boyfriend and
"sold for money." It was after this horror that she came to Oakland from Fort
Worth, Texas to live with her sister, with whom she has been living ever since.
Mina worked at a race track selling "hot dogs, chicken, hamburgers, and
popcorn" for "twenty-something" years before she went on disability due to an
injury she suffered on the job.

Mina is a Cherokee woman who grew up in Oklahoma, where she
attended an Indian Boarding School with her nine brothers and sisters. Her
mother died when she was young, and from that time Mina lived with her aunts
and uncles during the summer, and at the boarding school during the year.

Mina was diagnosed with cervical cancer in 1976, one month after her
daughter was born. She was treated successfully with a radical hysterectomy,
and has had no recurrence. However, she still has a great deal of fear surrounding the issue of her cancer. She has always felt that because her mother died young, and because she has cousins, aunts, uncles, and other relatives that have died of cancer, she will die of cancer at some point.

Rose

Rose is a 49-year-old woman who lives in San Jose in a very small one-room apartment with her “children” who are ten “rescued rabbits.” These rabbits were all found injured or abandoned, often missing limbs, and she has adopted them and made them a very important part of her life. Her immense love for animals also inspired her to begin volunteering at a veterinary office where she was eventually hired as an employee. She works at that office currently, and supplements her income by dog-walking and pet-sitting. Rose completed one year of community college when she was younger, and would like to go back to school someday. She is single, and the family she has in the area are her mother and her step-father who live in San Jose, whom she sees quite often. Rose describes her life right now as “physically stressful” due to working long hours to try to make financial ends meet, but “probably the least emotionally stressful” that her life has ever been.

Rose is of Canadian Indian and French ancestry, and grew up in southeastern Washington. When she was 17 she left home and went to Seattle, followed by moves to Hawaii, Canada, and finally San Jose, where her mother was living. Rose’s early life was difficult as she suffered emotional, physical and sexual abuse from her father. She described her early life as a “living hell,” due to abuse, alcoholism, and neglect.

Rose was diagnosed with cervical carcinoma-in-situ in 1996, after she
went to a Native American Health Clinic to get treatment for her asthma. She was persistently encouraged by the doctor there to get a Pap smear in a free program that was going on at the time. She was "shocked" at the result of the Pap smear, and very unsure about what to do next, due to her extreme mistrust of doctors and hospitals. She has had many problems with drug allergies in the past, and was very frightened about going under general anesthesia for the surgery. She went through the surgery under epidural anesthesia, that was complicated by her blood pressure dropping dramatically at one point. This caused her to panic and try to get off of the table, but she could not move. For her, this was the worst part of her experience. This experience was so traumatic, that she is not sure that she would get treatment if she were diagnosed again.

**Velma**

Velma is a 55-year-old woman who lives alone in Oakland in a one-bedroom apartment in a duplex. She lives across the street from her youngest daughter, who is 26 years old. Her other daughter who is 29, and her granddaughter, who is 9, live in Burlingame, about an hour away. She moved to Oakland from San Jose, due to her insurance coverage, and other constraints posed by her illness. She finds it very stressful living so close to her daughters, and does not feel that her current situation is very supportive for her. Velma divorced the father of her children over 20 years ago, and has been single, and a single-parent since then.

Velma is of Chickasaw ancestry, and grew up in Redding, California. Her parents migrated to Redding from Oklahoma, and she is the eldest of eight children in her family. Both of her parents have died in the last two years. She
has one sister who lives in California, and six brothers who now live in Idaho.

Velma worked for the Post Office as a letter carrier for much of her life. She retired around ten years ago on disability due to injuries she suffered on the job. At that point she decided to pursue her life-long dream of education. She got her AA degree, then her bachelor's, and then her master's in Social Work. These degrees are some of her proudest accomplishments.

Velma was diagnosed with breast cancer in 1993. She had not yet completed her master's degree at the time, and for the following two years she put in an incredible effort to finish that degree. She now has stage IV breast cancer (advanced, metastasized) which is currently "inactive." She has been in pain continuously since her surgery, and is very upset that she is not able to "use her skills" as a social worker. She would like to start a small group of her own for women with cancer.
Chapter Five: The Cancer Experiences

This chapter describes the "common story" that emerged in the analysis of the participant's individual stories, as told through their interviews. The "common story" can most simply be characterized as a story of change, of transition, and, in some cases, of metamorphosis. All of the women expressed that the landscape of their lives was transformed by their experience of being diagnosed, treated, and living with cancer. Although this transformation was not necessarily positive, it was almost always used by the women to create environments in which they were able to go about the consuming business of "healing."

The changes described by the women can be further classified as changes in certain relationships in their lives. The term "relationships" is defined here as the "attitude or stance which two or more persons or groups assume toward one another." The relational shift most discussed by the women was the shift of the relationship between themselves, as individuals, to the "world of medicine." By this I mean their relationship to doctors, nurses, hospitals, drugs, the conventional American medical establishment, as well as to traditional healers, traditional medicines, and "alternative," "complimentary," or "holistic" medical systems. The next most commonly mentioned shift was the shift of the individual women's social ties--their relationship to the significant people and groups in their lives. Sometimes these shifts in relationship occurred as evolutions or progressions, sometimes they occurred as a revitalization or circular return to a former configuration, and sometimes they occurred as a tragic disintegration.

The origin of these shifts seems to be specific needs that arose, for all of
the women in the study, directly out of their experiences with cancer. By needs I am referring to what they needed to "heal" (whatever that may mean to each one individually), and live with cancer. Some of these needs were, perhaps, preexisting in the women's lives and amplified during the period of illness, but most of them seemed to be new, born as a direct result of being diagnosed with cancer. These needs penetrated particularly strongly into their relationships with the world of medicine, and with the web of human beings that formed the social fabric of their lives.

In both of these areas, if a need could not be addressed by the relationship in its existing form, the relationship was reshaped, molded, adjusted, or radically altered in an attempt to meet the new, but pressing need. Often the effect of this shift was not limited to the intended relationship, but, rather, created a lasting effect on relationships in other realms of the woman's life as well. Namely, the realms of the woman's relationship to her "self," and sometimes, to her "spiritual" world. By her "self" I am referring to her relationship to her body, her psyche, and her inner construct of herself. By her "spiritual" world, I am referring to her personal inner beliefs. Acknowledging that the term "spiritual" is difficult to define and an overused term in our society, I think it is still the most appropriate term to characterize the women's changes in their beliefs and relationships regarding "spirits," "God," "the world after," and the more general belief that "all in life is precious" or sacred. All of the women participating spoke of some sort of alteration to one or both of these relationships.

Often the change in the relationship to the "self" or the "spiritual," sometimes rather dramatic, and sometimes very subtle, allowed the women to achieve a sense of "wholeness" in their lives, even when their social and
medical needs remained unfulfilled. Because of the large number of unmet needs existing in the women's lives, their time of illness was, and continues to be, a time of tremendous change in their lives.

The rest of this chapter will illustrate this pattern of relational shift in the women's lives, and identify the needs that inspired or forced particular shifts. The discussion will be organized into three parts: Shifting Medical Relationships, Shifting Social Relationships, and Shifting Internal Relationships.
Shifting Medical Relationships

All of the women participants in the study utilized "conventional medical care" to some degree. Half of the women sought only conventional care throughout the duration of their illness. Although some of them did obtain routine screening procedures, most of the women went to doctors or sought medical care only very rarely before their diagnosis with cancer. Not surprisingly then, half of them were diagnosed at a fairly advanced stage of disease. Almost all of them went to the doctor for an "unrelated" health concern, such as asthma, high blood pressure, excessive menstrual periods, "flu," or childbirth, and were subsequently found to have cancer.

Before introducing the needs that inspired women to revise their medical relationships, it is relevant to describe the nature of the change in these relationships. Many of the women described initial relationships with doctors, and other health care professionals, that were paternalistic in nature. Josie, speaking of her relationship before her experience with cancer said,

I usually just take the medicine the way the doctor gave it to you and he just tells you how to take it, and you take it, and you figured that you might be better.

The most profound pattern of change emerging from their 'medical histories,' was the progression from this obedient, paternalistic relationship, to a relationship of self-possession, control, and participation, in their medical care. For example, Rose, talking about the control she has developed in her interactions with doctors,

They tell me something, I say I'll take it under consideration, you know, I'll think about it, I will make the choice. If I choose what you have suggested, I'll do it, if I don't, I won't. And I've taken total control over everything--I went from basically being a person when I was younger who did everything, to doing nothing unless I am really sure, you know, wholeheartedly.

And then Luci, in the next quotation, clearly shows her pride in the
transformed power dynamics regarding her relationship to the world of
medicine. She describes what happened the second time she was
diagnosed with cancer:

So I did everything that everybody said, except now, I've got all kinds of
experience. I know exactly what's wrong with me and I know exactly what:
everybody's going to have to do and I'm going to orchestrate everything. 'You
guys don't even know what you're doing but, here, hang on and just go along
with me and we're going to have fun. Ok? You are, I mean, we're going to have
fun.'

Seven of the women discussed shifts in their relationships to the 'world of
medicine,' and each of them had some element of this type of progression.

The following discussion about the women's shifting medical
relationships will be organized into three sections: Communication, Respect,
and Integration of Care. Each section addresses a group of needs that led to a
shift in relationship.

Communication

A large number of the unfulfilled needs described by the women, that led
to a redefining of their medical relationship, had to do with a desire for more
adequate communication with doctors and health care workers. This includes
better listening, more straightforwardness, and more honesty. This section will
illustrate those needs as well as continue to describe the progressions in
medical relationships that individual women experienced.

Lornah's story illustrates the progression quite well. She attributes her
change in relationship, in part, to the communication gap between herself and
her providers. In her case, at the time of her initial diagnosis with cervical
cancer she was very unconcerned with the "world of medicine." She gradually
became very involved, and dependent, on medical doctors for the treatment of
her cancer. Then, eventually, she broke away from the "medical world," turning
to “Indian medicine,” as she discovered her personal needs for “healing.” This quotation describes some of her innocence, or lack of knowledge, when she was originally diagnosed with cervical cancer,

...I had not done a Pap smear, I didn’t know what a Pap smear was, I didn’t even know what a vagina was! We did not talk about those kind of things, and he did a Pap smear and told me that I had carcinoma of the cervix, and I did not know what that was either. I couldn’t talk about any of those things, besides they were in a different language. But I couldn’t eat, I was losing weight .... I didn’t want to go, I didn’t know what was happening. One day some lady up the street came over and said, ‘What’s all those letters sitting over there?’, ‘Some doctors saying something,’ I said. She asked if she could look at them and I said, ‘Sure, I don’t care.’ She looked at them and she asked me, ‘Do you know you have carcinoma?’ well I didn’t know what that is, I just assumed it meant some kind of flu. No one really told me. (Once they told you it was ‘cancer’, did that mean more to you?) No, I didn’t know what that was either. I really didn’t understand.

Her description speaks clearly to the lack of communication that drove many of the women to reconsider their alliance with the medical world. Communication between Lornah and her doctor was so poor at this stage that she was not even sure if she was supposed to return for further treatment.

At the next stage of her journey, Lornah became greatly invested in the advice and the opinions of conventional doctors. She describes another type of communication, in the following statement. She illustrates the pressure to adhere to medical advice that, although probably well intentioned, takes on a threatening tone.

But after that I had a tumor in my nostril, that the doctor told me was like spider legs going up into my cheek bone. He convinced me by telling me how hideous it would be if he didn’t take it out. He showed me pictures of how it would just disfigure my face.

It is worth mentioning, in order to see the change in her medical relationship, how Lornah very symbolically reclaims control over her treatment decisions at a much later stage in her care. She repossesses the story of her cancer that, up until then, and in the eyes of the “medical world,” was a story belonging in a medical chart which she had no right to even look at. This
happens after her doctor had forbidden her to continue seeing her medicine man, and to go to traditional healing ceremonies. She knew both of these things to be helping her immensely. Here she describes the scenario:

Dr. Lewis resented me going to ceremonies, and I was getting so sick from the chemotherapy. He told me I was believing in a pagan religion and that if I didn't stop going that I would have to find another physician. Well, William [the medicine man] told me that they were killing me. I wanted to quit chemotherapy, and I could not stop going to ceremonies anyway. So, when I was leaving, I went out to the front desk, and I said, 'I sure wish I had a copy of my chart so that I could show how the cancer went away,' and the receptionist looked at me and she said, 'I have to go to the bathroom.' So I got the chart where he wrote in the disappearance of the tumor, although 'patient refused the normal,' or whatever the special word was, 'orthodox, procedures.' So, that was humorous.

This description also speaks very directly to the need for "integrated" care that was expressed by many of the women. This will be discussed in more detail in the next section. It is relevant here, however, to mention that the women's reasons for desiring this care were often surprising. For many, the reasons seemed to have as much to do with the interaction with the provider as they had do with the search for more effective treatments or "cures." Rose illustrates this point as she talks about the transformation of her relationship with the "world of medicine" at a younger age, due to negative interactions she had at that time. She says,

I think the thing that I got angry about, too, was all of the stuff that was going on when I was a kid, and I would go to the doctors and they'd just say, oh, they'd tell my mom, 'She's just neurotic, she's making it all up,' you know, 'She's just in her mind, she's making it all up,' and I could feel all the stuff, the changes taking place, in my body. It wasn't until I went to an orthomolecular doctor that had tests to prove what I've been saying all these years, I developed a real dislike, then, for western medicine--a profound dislike for western medicine. The only MDs I would go to are people like orthomolecular physicians, and stuff, because they were the only ones that would listen.

She did not go to the orthomolecular doctor just because she thought he had better treatments, but because he listened. The importance of the provider listening was echoed by nearly all of the women, regardless of whether or not they were satisfied with the experience they had. For example, Josie, who was
very satisfied with her care, describes why:

They listen. I had a very good doctor, who listens, like we're talking now, it's like talking to a good friend, who listens to my issues, and complaints, and whatever I'm going through. If the medicine is not working, what needs to be done (that's great). And then I have a choice to take the medicine or not.

Rose said something very similar about a doctor that she had once had, and liked very much:

..see I had a doctor in Seattle when I was really young, when I first moved there--I had him for a number of years, he was white, but he was just, he was so understanding and so compassionate, and he'd listen, he'd listen to everything you said and he didn't have bad attitudes if he disagreed with you. He'd tell you, but he never, he had a good attitude about everything. I really got to liking him and then he and his wife who was one of his nurses, went to a clinic in Louisiana to head that clinic there, and so I lost him as a doctor and I just really grieved that.

Velma, who has transformed her medical relationship, since the advent of her cancer, by trying to limit the doctors she sees to women doctors, explains this transition below:

Women are more compassionate, they take more time to talk to you, and listen to you. The men doctors seem to want to tell you, you know, dictate to you. So that seems to be quite a difference to me.

She gives an example of this, by describing one of her experiences:

Ok, well, in San Jose, the doctors there, I had a very bad experience. The oncologist there was a male doctor, and I kept telling him about the pain I was having with my my, my, the pain I was having in my arm, and the pain in my chest, 'Well, that's just bursitis,' No one would refer me to physical therapy, to get physical therapy...and so, I was tightening up, the tissue here, and I got the remark from him, 'Oh, this is just the way it is when you have this kind of surgery', you know, that kind of attitude, and it didn't help matters at all....So, I had to get another doctor, so I got a woman doctor, and she was, ah, listened to me more, and she sent me to this doctor that dealt with, I forget what his specialty was, but he sent me to get physical therapy. So then I got physical therapy for about a week I guess, or two, you know, something like that, and it helped me quite a bit. It loosened up a lot of tissue, but I was still having pain. I managed to finish my degree. I don't know how I did that.

Besides illustrating the need for listening, this statement illustrates another issue that was very important in all of the women's interactions with their providers. That is the issue of being treated as an individual. In other words,
resisting being labeled a “cancer patient.” By resisting this generic label, a woman resisted the implication that because she had cancer, she would experience the same thing as everyone else that has or has had cancer, or has undergone, for example, a particular “kind of surgery.” This topic is expanded in the next section, but a brief explanation of how this manifested in Velma’s case is appropriate here. Velma felt that there was something genuinely awry with her arm, and she wanted to be recognized for her individual need for mobility. Several weeks later she was indeed hospitalized with an infection at the surgical site under her arm. Mobility was a necessity for Velma in order to finish her degree. She was very concerned about finishing the degree as her lifelong dream had been to go to school, and she was nearly finished. In short, she felt that she had particular needs and did not want those needs disregarded because someone viewed her as a terminal “cancer patient.”

Returning to the issue of listening, several other women had experiences in which they believed that the doctor had not listened to them, or dismissed their complaints. They believed further that this lack of attention had affected their health outcomes. Lornah talks about a time when she was evaluated and told she had irritable bowel syndrome, which turned out to be a perforated ulcer.

When I think about that pain, and how the doctor started telling me that he thought the pain was ‘in my head’ and that I just had an irritable bowel...my god, I told him, this is horrific pain, my bowel isn’t irritated. I’m telling you this is horrific pain. This resident doctor told me to tell him all about the pain again. I told him I had been beaten and dropped off unconscious more than once by my husband, and I knew what pain was...this pain was excruciating pain. I don’t know how long I laid there on the ground--I lost 13 pints of blood--they said the hole was somewhere in the duodenum, or the place where the two meet the duodenum. They couldn’t find it before because it was hidden in the normal x-ray or whatever it is they do.

A perforated duodenal ulcer is a condition that presents dramatically, with disabling, and excruciating pain. This condition will progress to death if not treated properly (Silen, 1991). Irritable Bowel Syndrome is a chronic condition
involving "steady or intermittent cramping" with alternating periods of constipation and diarrhea. This syndrome involves discomforting, but more tolerable pain, and is not an immediate threat (Andreoli, 1997). In Lorrah's case, the inability of the doctor to truly listen to her description of her pain, for whatever reason, resulted in a very painful and dangerous misdiagnosis.

In Mina's case, her doctor's lack of effective communication adds to her anxiety about the possibility of her cancer recurring. She had a hysterectomy as surgical treatment for her cervical cancer, and, therefore, no longer needs a Pap smear because she does not have a cervix. However, she is concerned about the cancer returning elsewhere, and does not understand why her doctor no longer gives her a Pap smear:

I told her about my [previous] Pap, and she told me I don't have to have a Pap smear no more. And it kind of scares me, because if she don't take a Pap smear, if I had cancer of my tubes or something, how am I going to find out if you don't take a Pap smear!

Other communication issues that arose for the women were desires to have the doctors be straightforward, and to be honest with them. Luci illustrates how she was never quite sure if her doctors were giving her the whole story:

And he said the same thing. He said, "You have any problems with your organs and stuff like that? And I've noticed you've lost a lot of blood". He looked at it just to feel it, and he must have really known what it was because, I mean, he did an acting trip on me, but I knew that he wasn't telling the truth yet.

Beatrice talks about her interaction with the doctor that first diagnosed her with colon cancer:

See, my doctor that I was going to at the time, she said, 'We'll give you this test, right now. If it turns blue, you're ok, if it doesn't turn blue, it's not ok.' So she gave me the test, and it didn't turn blue! So I think, 'ok'. And she gave me the exam and she didn't tell me anything. Later they gave me a letter, and I went in the car and opened it, and it said I had cancer! (They told you in a letter?) Yes. So, I went home and I didn't believe it. I stood in the middle of my living room and looked around.... It was not real to me. (oh) But that doctor felt the tumor and she didn't tell me.
The unreliability of the test, and the failure of her doctor to communicate openly and honestly with her, moved Beatrice into reevaluating her relationship with the medical world. Eventually, she came to believe very little of what doctors said. Moreover, she redefines her dynamic with doctors quite dramatically. She tells of an incident before the preceding one, when several tumors were found in her breast:

... several years back, I had a red pimple on my breast, so here I run to the doctor, and the doctor examines me, and he tells me that he has to cut my breast off. Just like that. Dr. Parker. And, ah, he says you have to go for surgery because you have a tumor there. So I said, 'ok.' And I tell you, Ginny, at that time, I was just as naive as naive could be. So here I go. So he says 'Well ok,' just before I go into surgery he says, 'Well we're going to have to amputate your breast, how do you feel about it?' I said, 'Well, its ok, cause I can always use a falseie.' That's how stupid I was. Anyhow, I went up to surgery, and the first thing I do when I woked up, I looked, and it was still there. So, when he came to visit me that evening I said, 'I see I still have my boob.' He says, 'Yeah, well I took one tumor out, and another one that was soft, about the size of a dollar.' That was all he ever told me. Suppose I would have really believed, 'oh, he's going to amputate it.' He would have done it. Well, I still have it and I intend to keep them.

Here she illustrates her past "naivete" in her relationship to the medical world. She blames this on her own stupidity, but points clearly to the lack of communication with the doctor.

A story occurring much later, during her struggle with colon cancer, illustrates the change that has occurred for her regarding the power of medical authority versus her own personal opinion.

And I have to tell you this story, I am glad to have my body working, because one time the doctor said I need a colostomy. I went in there, and they said to bring the whole family, and everything, ohhh, but the doctor said I need a colostomy, and I said, 'No! I will not.' My kids were there and he tried to talk to my kids, to convince me, and my son and my daughter said, 'Listen to the doctor, he knows what to do, please, Mama, listen to him.' So I said, 'no' and he started again from the beginning to tell me what I need to do, and I was not changing my mind, and we were going to surgery. So he says, 'Beatrice, why not? Why not get it?' And I said, 'I'll tell you why not, because I don't want anyone to squeeze the shit out of me.' And he laughed, and the kids laughed and I was laughing, but he said, 'oh, come on,' and I looked him right in the eye and said again, 'I don't want anyone to squeeze the shit out of me!' And he said, 'Ok.' I mean I don't want no stinky bag hanging out the side of me. So, then my kids tell me during surgery he came out and asked them if they shouldn't just do it anyway. They told him he better not,
because they didn't want to hear it from me.

This story illustrates not only her new relationship to medical authority, but also the somewhat heavy-handed persuasive techniques on the part of the doctor, who tries to get her family to convince her to get the colostomy. Even after the decision is made the doctor considers overriding her authority while she is unconscious in surgery. She also illustrates, through this story, the need many of the women felt for humor around the topic of their illness.

Towards the end of her treatment period, Beatrice had developed a relationship with medical opinion that could probably be characterized as total disregard. Although the doctor told her she had a sixty-six percent chance of surviving, the statement below illustrates how she was now seeing the facade of medical knowledge more clearly, and challenging the truth of the doctor's prognosis.

No, I didn't think [that I would die]. I knew what the doctors said, and I asked him, 'What are my chances?' What are they doc?' He looked right at me and said, '66%,' I looked at him and I said, 'Are you telling me the truth?' He said, 'We don't know.' So, I knew he doesn't.

Following this, her focus was on "pray[ing] to God, to be back to the ordinary."

Velma also questioned the honesty of her doctors after she asked them if there was any other option for the treatment of her breast cancer besides surgery.

It was a lot of confusion, yeah. Cause I just felt that they were, it was just like no one would tell me exactly. I felt that they weren't very honest with me. I felt like I was put in a corner. I had to have surgery.

She tearfully described the developing frustration that led her to search for answers herself. This search left her feeling perhaps even more frightened, confused, and trapped.

I went between three or four doctors, you know, trying to decide, what, you know, what to do. I never did get a satisfactory answer. I did some readings and
research as best I could. And, ah, the surgeon said that he wouldn't even operate on me, unless I would agree to have this dissection of lymph nodes, cause I was fighting that. I didn't want the lymph node dissection cause I found out that that's nothing but, ah, a means of just diagnosing, its just, I can't even think of the word right now, that I want to say. They just want to see how far the cancer went, that's about it, you know, collection of any cancer cells or whatever. Its just diagnostic that's all it is. And it makes you disabled. And this one book that I read said that is something that's not really necessary, and that it just leaves women, you know, handicapped.

Velma describes the pressure, that other women described as well, which led her quickly into the operating room:

I felt like a gun was put to my head, so I had to do what the establishment suggested, and I'm not happy about it. I felt angry at the medical profession, so to speak. I do not like men doctors. I have female doctors. All my doctors now are female.

In this quotation she also describes, as mentioned previously, the manner in which she alters her relationship with the world of medicine--by choosing to go to women doctors. The following statement further illustrates the extreme pressure exerted by the doctor. The statement also verifies Velma's eventual belief that because of extreme pain, and consequent disability, she was correct in not wanting to do the procedure that she believed would unnecessarily mutilate her body, and only be useful to doctors.

So I had to let them do what they wanted to do, otherwise, this doctor said he wouldn't even touch me, unless I let him do this here dissection, and I've had trouble with my arm, ever since. I've been in pain, since surgery.

Ada, who had a trusting relationship with a doctor she knew well prior to her diagnosis with cervical cancer, spoke about how the anxiety of the diagnosis was greatly decreased because her doctor "explained everything."

Actually at the time, I just thought, cancer, cause my dad died of cancer, and it was like 'wow' I sat there and cried for about five minutes, and like I said, then I thought well, 'What's next?', and that's pretty much, like, well, what's next. You know, cause they explained everything to me, you know, what they were going to do, and what the chances are, you know, and this and that, and so it helped having a good doctor and stuff, too. You don't get scared and you think, you know, 'Oh I'm going to die', or 'I'm going to be this or I'm going to be that.' (yeah) So, I didn't really go through any of that. I felt more positive, but it was, too, like I said the doctors were really good and they explained everything, as we went through the
treatments.

This quotation is important not only because Ada's perspective underlines the significance of good communication skills on the part of the doctor. Her assessment also shows that these skills may have been an important factor in overriding an extremely powerful, common contributor to the women's fears about cancer—the cancer death of a close family member. A good deal of the fear that many of the women mentioned when they were first diagnosed, was related to the fact that they had watched a close friend or family member die of cancer, and they believed that the condition was hereditary. It is important to note, therefore, that although her father died of cancer, this fact did not amplify her fear, due to successful communication by her doctors.

Luci illustrates in the following quotation how the ability of her oncologist to be completely straight with her was really the "only thing she cared about."

So, Dr. Panetta finally walks in, and she's tough. She is really tough. I just looked her and she was so...she actually lit up my whole life right in front of me. It was so cool! I mean it was just like, she's tough, and she could say 'fuck', and she could say 'goddamn', and she was doing all that, and but, Lisa Wong was the same way too, and they're just getting...so Dr. Panetta looks at these CAT scans and all this stuff, and there's a letter from Dr. Harper. And he had given me 30% chance of living in only 3 months - that was the diagnosis. So she said, 'You want to read this? I said, 'Sure.' She said, 'You want me to show you an idiot?' She said, 'Because you know why? I'll tell you.' She said, 'I'll guarantee you, if you'd seen this letter before we were here, you wouldn't have come, would you?' I said 'No.' She said, 'I'll show you a jackass. Idiot.' I said 'All right', so I read it. She goes 'Who the hell does he think he is? He's not a cancer doctor. How in the hell would he know what's going on with you and not going on?' She said, 'We're going to go through this and we're going to see what we come up with.' And I'm just going, 'Geeze, I've got some woman who is just as strong as me, both of them are just as strong as me, and we're not going to bullshit with each other.' And that's what I needed. And that's the only thing I cared about.

Many of the women also cited the lack of communication regarding possible pain or consequences of treatments, as something that caused them grief. Rose said,

I mean I just think if he would have talked it through with me, 'Well, this might hurt', he never even mentioned I might have pain from the epidural, nobody even said a
word. Even the nurses up at the hospital, they never said a word. Even the anesthesiologist never told me I was going to be in pain, nobody told me.

Luci had a similar complaint:

And they're always telling me, I'd go... 'you're going to tell me this doesn't hurt, huh?' And I'd say, 'would you guys quit saying this doesn't hurt? It really hurts.'

Velma felt the potential after-effects of her radiation were not effectively communicated to her:

I had the most awful radiation burns, no one prepared me for radiation, for this. They claimed there were pamphlets of some sort, but no one told me, they just told me, 'Well, the skin may get red,' but they never told me that the skin would disintegrate, I guess, is about what happened. I just had one big open sore under my arm. Like a tenderized steak, a red steak, was what it looked like, the burn was just unbelievable. Yeah, I had an awful time, ahm, healing myself.

And Lornah talks about an unsuccessful reconstruction of her breast, that she would have avoided, had she known the consequences:

They just butchered me then, they really did. Now its different sometimes. But they will also do an immediate reconstruction and they did that for me--it was the most horrifying, disgusting thing--they tried to save the nipple, and it rotted. Oh, it was so disgusting. They couldn't take it off, they had to wait till it fell off. Now I would just say, 'Leave my tits alone! They've got falsies down at Wal-Mart with a nipple right on there'. Oh, it was sick.

This perspective is also another testament to her acquisition of power in the medical relationship.

Respect

In addition to improved communication, another issue raised by the women regarding their relationships with their providers, was the issue of 'respect.' The women desired respectful relationships that would ensure trust and sensitivity. In some cases, lack of trust, or sensitivity, seemed to be due to the aforementioned lack of effective communication, but in others, the women
felt it was due to a fundamental lack of respect. For example, in the scenario described below by Lornah—which she interestingly describes as an ‘out-of-body experience’ as it was labeled by her doctors—she confronts a fundamental lack of respect that the doctor had for her body, as well as for women in general.

Another thing that’s changed, is that I had an out-of-body experience, it was documented. I was getting my second breast surgery and I was laying there on the table and I could see, but I couldn’t move or anything, and I saw this blood going up the doctors hand, and I heard him say, ‘It’s a good thing she’s had kids already, she won’t be needing these anymore,’ and the nurse asked him how he would feel if he got his balls cut off. He didn’t say anything, but I could remember it clear as anything, and as soon as I came to, I started screaming at the top of my lungs, saying ‘That son-of-a-bitch, what does he know about me?’ And I was screaming that I wanted to talk to Dr. Meyer, and they sent a psych nurse down, Lily Harris. All the nurses were looking in, because I was making such a racket, and pretty soon they figured out what was going on, so another psychiatrist came in and had me record every detail I could remember, and that’s how they documented it. They couldn’t believe it because I had had way too much of a certain kind of medicine to be conscious, there was no possible way I could have woken up, and so they said it must have been an out of body experience, that was the only way to explain it. But Dr. Meyer wasn’t allowed in my room, he couldn’t even look in. How insensitive of him!

In the statement below, Rose illustrates her lack of trust in doctors, especially male doctors. She sees this stemming from a fundamental lack of respect she felt her doctor showed her during surgery, as well as her distrust of male gynecologists in general:

It was just like, ‘Slam, bam, lets get this over with, I’ve got other patients to go on to, I just don’t have time for you.’ Its like ‘Excuse me, but you’re talking to a lifetime of trying to cope, with horrible situations, beyond your imagination,’ (yeah) And don’t come in here expecting me to cooperate with you when I don’t know who in the heck you are, and I don’t even know if you like women. Just cause you’re a man doctor in a woman’s field doesn’t mean you even like us, I’m not convinced that male gynecologists like women. They may think that women are just easy prey for them, or even money for them. They might be using us in just another way. How do I know, you know, so ‘why should I trust you?’

Rose goes on to talk about a veterinarian at the veterinary clinic where she works. Here she cites a fundamental lack of understanding as a reason for being skeptical of male doctors:

I remember the one male doctor once saying, ‘Well I don’t think the pain of childbirth is really that bad because women tend to recover, adapt, to it ok.’ And
one of the other doctors said, 'You know what, I don't think you have a right to even have an opinion about this, because it's something that you will never experience, so just shut up.' All those women are pretty vocal, so he doesn't get very far with stuff like that, but he's, having worked around an entire female staff for all these years, he's still, as far as education on women and women's issues, is a totally, is totally.... lost, I mean he just doesn't get it! And you just think, my god, if he's representative of the majority of men, we're in trouble, you know. He's a highly educated individual.

Instances such as these, combined with her history of sexual abuse, have made it very difficult for Rose to trust doctors. And trust, as she mentions in the next quotation, is what she ultimately needs to continue pursuing medical care.

Yeah, so anyway, I'm grateful that I went through it, to get it taken care of, but now they've been pressing me, 'Well you should get a mammogram.' And its like, I don't want to do this, I'm really resistant. I just, I think if I had a doctor that I really thought cared about me, and that I really trusted, really trusted fully, I wouldn't be so resistant.

Luci felt that she was not given respect in the following encounter with a nurse, because of her drug use. She had come to the hospital because of excessive bleeding. She relates:

So when they brought me in, laid me in one of the gurneys in the hallway. And the nurse asked me, 'What do you think you have?' I said, 'Well, I think it's probably an overdose of cocaine.' So she's in a matter-of-fact going 'Oh jeez. Well, all right. I know how to handle this kind of woman - she's all messed up - she's just an overdose.' And she kept telling me . . . she was just patronizing is what she . . . she was. I said this is a fine thing. I'm not really feeling too good here, and I don't really like to be patronized. Can you just . . .

The issue raised in this quote is one of disrespect by stereotyping. This is very similar to the issue brought up about being labeled a 'cancer patient,' that will be discussed in the section on shifting social relationships.

Integration of Care

Another issue that came up with almost all of the women was the wish to integrate their care, using practitioners other than conventional doctors, and
medicines other than conventional drugs. For several, like Lornah, their experiences with practitioners of other systems of healing occurred after conventional doctors had ‘resigned their case.’

...he said he saw a malignant tumor on the right. And he was right, and then I had a radical mastectomy. They also took out 13 lymph nodes, and 9 of them were abnormal. He resigned on my case then and told me that he could not help me anymore, I was a terminal case. Again, I started calling up William, the medicine man who used to give me medicine, and doctor me.

When the cancer “went into her bones” Lornah began getting treatment almost exclusively from the medicine man, and the system of “Indian Medicine.” The next statement exhibits what this system of medicine could offer her that the ‘conventional’ system could not.

He began doctoring me most when it went into my bones. It took two and a half years of continuous-sometimes 7 nights a week--ceremonies to help me. I'm so lucky. I'm super lucky, I couldn't have lived without it. Nowadays, I'd be dead already. Most people can't get it, its very sad. But my family situation was insane, and I know that I was going down a different path without the ceremonies. That brought my family together.

She states, also, her belief that integration of the two systems of medicine would be helpful to many people:

If medicine men could be infiltrated into doctors, then a lot of people who couldn't get help, could be helped. A lot of people.

This system has gradually become her main source of care, as well as a deep source of strength for her. She states,

Now, because of my belief in Indian medicine, I give my life to the alter, to the pipe. Medical science has given up twice on me....I don't give this as a personal strength. It has nothing to do with me, its the spirits deciding. I should have been dead by 1985. I don't over give credit to human beings...its God, or whatever you like to call it.

Velma talks about how her insurance would not cover 'integrative' medical care. She found a clinic for low-income women offering “alternative" services that she began attending regularly. She cites the need for a system of care that would address the emotional burden she
had been living with since her diagnosis of breast cancer:

I started going there last October actually, and they do, acupuncture, massage, energy work, visualization, herbs, they give you herbs. And I've been doing a whole lot better since I've been going there. Yeah, cause when I first started going there, my emotions were so, I was so...my emotions were just on the surface. I was in constant tears. I couldn't cope with, I was having problems coping. My youngest daughter lives across the street, and she helped me get this place. I don't particularly like living across the street from her.

Five of the women participating brought up the fact that they felt that they were more sensitive to drugs than most people. Most of the women commented that they had "reactions" to drugs, and at least three of them experienced rare side effects of drugs that caused permanent damage to their bodies. This prompted many of them to seek relief through "alternative" therapies.

Velma relates her experience of developing pulmonary emboli from Tamoxifen, as an additional reason for seeking care at the above mentioned "alternative" clinic:

The Camosin is not what it's all crooked up to be. Tamoxfasin is not good. (Tamoxifen?) Yeah. Yes. They claim, I mean they know what the major side effects is, but I happened to suffer one of the major side effects. I know I wasn't taking it for more that eight months, maybe less. And my body started creating blood clots, in my lungs. And I went to the doctor, my oncologist hospitalized me, cause they couldn't figure out why I was having so much pain in my chest. And she wanted me there under observation. Well, they found out I had blood clots in my lungs. I ended up being there for a week. And then this other medication that I was taking...Well, I couldn't handle it. It started closing down my bowels. And then I had to be hospitalized for that. And my resistance is so low, in general, its so many times, I can't even begin to tell you how many times I've been hospitalized. I'm just thinking of the major times.

Josie, who experienced a rare cardiac toxicity with a chemotherapy drug, illustrates in the following statement, the evolution of her relationship with conventional therapies. Josie was quoted at the beginning of this section as saying that, in the past, she "just [took] the
medicine the way the doctor gave it to you and he just tells you how to take it, and you take it, and you figured you might be better.” Here, she explains her current feelings on the subject:

I'm paying attention to side effects, and risks of medication. I'll talk to my doctor first and find out what the prescription is supposed to do and the risk, the side effects. I have to know all that, I'll read the instructions when I get them from the pharmacist, and I have a book also, that describes 801 prescription drugs, and if I'm not sure about it, then I don't take it if I feel uncomfortable. These are things I've never done before in the past....I have a low tolerance for medications. And the side effects with the cancer treatments has just been too much for me so, you know, I'm in tune to that. And they even commented that I seem to know my body. I listen to little signals, when something is not right. And if I take a new prescription drug, on the second day, if I feel worse, then I need to stop that. Like, they gave me a pill, I think it was called Lysopril, and it tends to make the blood pressure go down too low. It brings it down, but mine went down too low. I took it for two days, and I stopped and let my doctor know, that there was no way I would take that drug again. (that's good) Yeah, I can't take it. And I guess, according to statistics, it works for some people. It doesn't work for me, so I'm learning that too, about my body. Because it's written, documented, that this drug works, for a certain group of people, doesn't mean it will work for me.

These difficulties with conventional medicines led her to become more interested in traditional therapies. In the next quotation she illustrates her growing interest in the medical system of her ancestors:

And its making me embrace my culture more. A lot of herbs and medicines that I grew up on, and my mom made, and my grandmother grew different types of herbs and roots and berries in our backyard. And so you're pretty much back to the basics, and you think, well, yeah, these things really do work. They really do work.

Several women talked about a need for information limiting them from using other systems of care. Velma said:

Maybe, if I knew more, I would have opted to do other things. But I had one handicap, and that is, I didn't have the resources, or the information. Cause, my insurance wouldn't cover it. They wouldn't cover for acupuncture. They wouldn't cover any alternative medicine. So, I had to do what...I had no choice about it. And I'm not too happy with the consequences of it. Maybe it saved my life, supposedly, but the consequences of the surgery is not to great. I was changed radically.

She goes on to describe her interest in “alternative healing” systems that would look at “all the parts of the person.” The following quotation also
illustrates the means by which different systems of medicine are being advertised in popular culture. This advertising allows for a sparked interest, but not a genuine access to information for women seeking alternatives to their current treatment regimen.

Oh, I wanted to tape this, there was a lady I saw on, I like her so much, Jesse Raphael, she had to do with alternative healing, it was about people who do alternative healing professions. And this woman did (she wrote it down)...naturopathic. Have you heard of that? (uhuh) Yeah, it said she was a naturopathic physician, she works with herbs, and all kinds of different things. And I thought that this was so fascinating, what she does, and I thought, wow, that's the kind of doctor I need. And I've never heard the word before...But that's something I'm really interested in looking into. I think there's different ways of looking at healing. And the women doctors seem more interested in looking at the spiritual aspect of a person, you know it goes together. You've got to look at all parts of the person. Not just giving out medicine, you've got to take care of the spirit as well. It's important. I think women are more sensitive, that it all goes together. My oncologist, she's great, I wouldn't have any other.

At the end of this statement, Velma mentions how, despite her longing for a different system of medicine, she really likes her oncologist. She said that the reason for this was that she "takes the time to talk to me." Her recommendation seems to be that she would like to integrate systems of care in order to get a more caring system overall.

As Rose illustrates in the next quotation, she had already been utilizing several systems of care, before the advent of her most recent illness. This statement comes in response to the question, "Did you ever go to a medicine man, or anyone like that, for treatment?"

I probably would have if I would have had the opportunity to, but I didn't have that opportunity. But I was involved with a spiritual teacher for a number of years, who did healing, and also one time, went to a psychic healer, who had studied in the Philippines, and a friend of mine both and I went, and that was a very...she actually took a whole group of, I was having trouble swallowing, and she took a whole line of growths off my vocal cords, she stuck her hand right in my body and pulled them right out, I could feel her hands inside my body, and it was very profound. The body really goes through some changes after that, and that was very

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profound—it really helped, I got a lot better.

The final quotation to be presented in this section is from Lornah. Her statement reveals her view of what she needed to heal that is not offered by the system of conventional medicine and modern technology:

All living things have the power to heal themselves—a dog will go off by itself and heal itself if you leave it alone. If its going to live, its going to live. We’ve become so great in technology, we can’t let someone go off and heal themself.

This statement illustrates Lornah’s need to be left alone, to some degree, in order to heal. As will be illustrated in the next section, not being "left alone" was a problem the women had not only with conventional medicine, but with many of their social relations as well. The women had to fight on several levels to get the time and space they needed to heal.
Shifting Social Relationships

The shifts in the social relationships of the women in the study were often very dramatic. Several times the changes involved the end of a close personal relationship or a marriage. Other times the changes involved putting restrictions on interactions with parents or children. In at least five cases, women moved significant distances—to other cities, or in one case, back to a reservation—at some point during their illness. Several of the women never resumed sexual intimacy after their illnesses and surgeries. Not all of the relational shifts were that dramatic, however. Some shifts involved events such as the pursuit of a new friendship in the hospital, or decreasing responsibilities in caring for a grandchild.

The women seemed to alter their social relationships in accordance to particular needs, and most of these needs tended to fall into two main categories: the need for independence and the need for optimism. Relationships that did not allow the women to be independent and optimistic called for revision. The changes in the women's social relationships are illustrated in the following sections, titled Independence, and Optimism. For each woman, the pattern of increasing or decreasing importance of a certain relationship in her life depended primarily on the flexibility of the person or group at the other end of the relationship. Those people who were not flexible enough to adapt in the face of changing needs required an energy from the women that they simply did not have at the time of their illness.
Independence

The word "independent" is defined by Webster's dictionary as:

1: a. not dependent; not subject to control by others  b. not requiring or relying on something else : not looking to others for one's opinions or for guidance in conduct  c. not requiring or relying on someone else (as for livelihood)  d. showing a desire for freedom  e. not determined by or capable of being deduced or derived from or expressed in terms of members of the set under consideration....neither deducible from or incompatible with another statement (1987).

The women desired independence as described in nearly all of these definitions. They desired physical and financial control of their lives that would make them "not dependent" on their family or friends. They wanted to be free to have their own feelings and opinions about their illness. They also had a strong need to be independent as described by the last definition: "e. not determined by or capable of being deduced or derived from or expressed in terms of members of the set under consideration." This definition may initially be seen as one of the less obvious needs, but it was arguably, from the women's perspective, the most important. The "set under consideration," in this case, is "cancer patients" or "cancer victims." The women did not want to be "determined by, deduced, or derived from, or expressed in terms of members" of the larger group of "cancer patients" which they became a part of, upon their diagnosis. The women were extremely conscious of the stigma carried by the label of 'cancer patient.' They wanted greatly to be considered as individuals, independent of this larger stigmatized, and "doomed" group. They wanted others to treat them as individuals dealing with a disease unique to them.

In their minds, the women struggled to revise their own definitions of a "cancer patient." They were more successful with this change than they were at changing the definitions of others. Some of the biggest troubles and
heartaches experienced by the women came upon painful confrontations with the deeply entrenched and narrow "cancer patient" definitions of the people around them. The beliefs of others often inspired additional requirements of independence for them, such as living alone. They understandably did not want to be under the care, or in the presence, of anyone who had written them off as dead.

Several women talked about this need to be "alone," and independent, in the context of the reactions of others. Some of the women's friends and family believed that part of being a "cancer patient" was that at the end, the "cancer patient" dies. Here Luci talks about the devastating "aftermath" following her first cancer:

But the worst part of it is, I wished I had died, to tell you the truth, than had to go through the aftermath. The aftermath of being alive and surviving the cancer was so bad, that I could hardly deal with it. I started using drugs, I started doing all kinds of things. . . just being afraid - I was so petrified. So then I went onto destruction derby. . . . 'I am absolutely no good because I had cancer.' And I could see the reaction on people's face, 'Aww, poor Luci. She's had cancer - she should be dead.' And the family here was my sister-in-law, she lost her son to cancer when he was 21 years old - that was 20 years ago. And she was actually mad at me.

Lornah also talks about how those close to her cannot accept that she is living with her cancer, and the effect that has had on her:

I carry a lot of guilt complex these days. Because many people have the same cancers diagnosed as I do, and they don't make it. I wonder, 'Why was I chosen to go on?'. And people get mad at me. The family looks at it, and other families look at it, and they wonder why I am still alive. I have had many people...one friend who wonders why her relative should die of the same cancer and I am still alive. I know she is mad, but I don't know why I live and others die. I was challenged one time that I was faking my surgeries, by my adopted mother and step-father. They thought that I was making it up, and my step-father was an emergency nurse, so she came to me and said, 'I hate to ask, but can you show John your chest, so that we can see.' I ripped my shirt off right then, and they were shocked. It totally shocked them. They couldn't believe it. And I was mad, but nobody knows how it hurt inside me--the pain, and then the doubts and people who think you faked something, especially because you're not dead. It hurts that they can't see how much it hurts, that they have to see something. It hurts that they don't understand. And they do not understand even then, that I want to live today living! I'm not dead, and why should I spend my time being morbid and sad. I want
to enjoy life.

Here Lornah brings up the need to enjoy life, and to be positive and optimistic. This need is also echoed by many of the other women, and will be discussed in the following section, Optimism. The inability of Lornah's, relatives to accept her as a cancer patient with an independent experience and prognosis, was a theme that recurred with several of the women. Luci continues in the next quotation, describing how she severed her relationship with her foster mother, because of her mother's bleak outlook regarding her prognosis:

I wouldn't see her. Because every time, every time during my cancer -- she would call and she would get all these articles together and she says, "You're not going to survive." I mean, that's real cute. I like that one. And she kept doing all of these statistics that she had read and everything. And I told her, I said, "You know what? Don't you fucking call me no more". I says, "I don't know what the hell you think you're doing," but I says, "I'm not dying for you, I'm not dying for anybody."

Josie talks in the next quotation about the reaction her sixteen year old daughter had to hearing that her mother had cancer. Fortunately, in this case, this reaction did not end up negatively affecting their relationship. However, it does illustrate the kind of pressure that the women had to deal with in terms of the reactions of others. This was a strain that, although it was handled successfully by Josie, could be potentially very taxing on a woman still trying to make sense of her illness for herself. She describes:

I told her after she got in from school, and that was like another bomb had hit our household, and her being so young, she felt it was her fault. She felt that she was being punished, I was being punished for what she had done as a kid, maybe she didn't try hard enough, had done better in school, not saying her grades were low, but that's how she felt. Kids react to stress different than adults so, I know that. She blamed herself.

Josie illustrates further in the following instance, how the beliefs of other's stemming from widespread cultural beliefs, make it difficult to accept having cancer. Talking about her daughter, she says,

She too, knew about cancer from watching medical programs on cable, and how
they stress that it starts to spread, and it comes from smoking and drinking, so in her mind, its like, her friend's parents, they smoke and they drink, and they don't have cancer, why is her mom suffering like that? (yeah) And that was really hard for her to deal with. Especially when you're taught in school, she went through the DARE program, 'say no to drugs,' so that was a firm belief in our household. And she went through the program and got the certificate. So, we're going 'Wow, something wrong here.'

Another element of wanting to be independent during the time of illness was a desire expressed by some of the women to remain anonymous about their disease. Several of the women, like Beatrice, did not tell anyone until they were forced to.

So, you told other people when you got cancer?

Nooo! Because I didn't want people to think I was weak! I didn't want them to feel sorry for me and to know I had cancer. I wanted to be strong. I did it all by myself. I told everyone to go away and I drove myself to chemotherapy and I was sick, but I did not want to be sick because I felt like it was weak. I never cried.... But I didn't tell my kids, I never told anyone. My kids found out because I had to tell one of my sons because I needed a blood transfusion (oh), and he told all the rest. I told him not to, I was mad at him.

Although Beatrice said she was not afraid of how others would react, she mentioned at an earlier time that her son was "more upset" than she was upon finding out that she had cancer. She elaborates on why she did not want to tell her children:

I just didn't want to burden them, you know. I didn't want them to try and help me. Beatrice anticipated the reaction of "help" from her children, and knew that she did not want it. She may have had other motivations for avoiding this situation, but it was clear that for many of the women, remaining anonymous was a direct attempt to avoid the toxic reactions of others. Luci describes how she lost people in her life because she revealed to them that she had cancer, and how she has come to terms with that.

You know, I wish I couldn't even have said anything, said anything about it, you know, I wish we could just live without... But, you know what? That's ok, because I probably didn't need to be with them anyway, you know, if they're that shallow. And, you know, if they -- if people -- but, that's what the whole concept of that
word cancer - if that could be eliminated out of our vocabulary and without it being death. It's a death word. It always is.

Rose talked about the effects following the disclosure of another occurrence in her life over which she had no control, being sexually abused as a child:

It has caused me nothing but problems since I let it out. It caused my mother tremendous.....an overwhelming feeling of guilt, like she should have known. She should have done something, ahm, and it turned my brother against me for a while...I look back now, and it hasn't done anything they tell me is useful, all its done is make people think that I'm weaker, that somehow...

She continues by describing a discussion she had with one of the veterinarians at her work. This story, although it is not about the disclosure of her illness, is very relevant because it reveals the potential danger of exposing oneself as a member of a stigmatized group--whether that be 'sexual abuse victim' or 'cancer victim.' She recalls,

He said something like, one day, he was telling me about, they're a very strong Mormon family so they want their kids to all marry Mormons anyway, but he was telling me for a while how his one son was dating a girl, who had been molested and abused as a child, her family was abusive, and he really liked her, but she ended up marrying somebody else or something. And he says, 'And I was always kind of glad, because you don't want your kids marrying somebody with that kind of baggage.' And I thought, 'So that's what you think of me, so what somebody else did to me now, I'm dirty, because of what somebody else had done to me, you wouldn't think that I was good enough for one of your sons to marry because of what somebody did to me!' And I thought you know, that's the way most people think (oh, god) that is, that is the way most people think. And I can tell that people think, 'Well, this happened to you, so somehow you're not quite as clean or nice or whatever, as you were before, you know ,we found out.' And, no, if I had it to do over, I never would tell, I never would. I feel like it has ruined my life by telling. I feel like people think less of me, I've actually lost some people in my life because of telling them too much, and I would never tell, if I had it to do over, because nothing has ever happened to him, nobodys ever thought badly of him at all, its all come back on me 100%.

The potential reactions of others were mentioned not only in relation to their cancer, but also in relation to the women's bodies that had been altered by cancer treatments. Lornah describes,

How do you tell anyone? I mean, I'd broken up with my husband, after I had a hysterectomy. It was never a marriage after that, and what do you say to someone
you just meet, 'Oh, excuse me, I don't have any breasts,' so they know right away and can decide if they want to...and I don't have anything down there either...

Beatrice talks about the discomfort she experiences due to the reactions other people have to bowel problems she has developed as a result of her cancer treatment:

And I have the same thing with gas, I can't ever tell when it will come. The other day I was in the store buying something and it let loose. I felt bad and I walked away from the counter and then I saw the boy at the counter call over the other girl and then she made a face like this, and then they laughed. I think he was pointing over my way, but I felt bad to make them smell that, to make the store smell that way.

Several of the women mentioned that their need to be alone and independent was, in part, motivated by a need to decrease their responsibilities. They talked about needing to conserve their energy in order to heal, and being unable to deal with demands they dealt with in the past. Velma had to revise the relationships she had with her daughters because, as she said,

It's difficult for me to cope with a lot of stress. My eldest is enough to be stressed over. My daughters are just beginning to really realize, that stress is something I can't, their stress, dealing with their problems, I can't do it, much, I can't do much of that, too well. I deal with my own, and as I say, I have good days, and then I have days that are not so good.

Velma has almost the opposite problem that Lornah and Luci have, in that her daughters do not expect her to be dead, rather they feel that she should have more control over her breast cancer:

People don't realize that family don't really understand. My daughter who's 26, my oldest is 29, she seems to be beginning to understand more than my 26 year old, but my 26 year old always had the attitude, 'You're not an invalid,' sort-of attitude. And I have a hard time keeping up my house, or even doing daily things. I'd like to do more....But, it's been real tough. My family don't really understand, and Janet, I know she's in denial, both these girls have been in denial. (about how serious?) About how serious it is, because Janet, my youngest, seems to think that if I eat certain things, and if I take herbs and do different things, that I could overcome it. The thing is, I could eat herbs every day and it isn't going to do much, cause I'm stuck, kind-of stuck, because the medicines I take, are not the greatest things to take, but I just don't seem to have much choice.

Velma had to move from San Jose to Oakland because her "insurance is up
here.” Living closer to her daughters, because of the move, has been very stressful for her. Because of incidents such as the one below, she has slowly had to withdraw herself from the lives of her daughters:

[My daughter] had her car towed the other day, because of parking tickets, because she works in a very difficult city, which is San Francisco, and where she works, there is no place to park. When the garage is full, she can’t even get a spot there. We had a heck of a time, I had to go borrowing from different people to get her car out of tow, and paying all the parking tickets. That stressed me so bad, that my body was reacting, and I was just...I was reacting, and it’s something I don’t have control over. Some stresses (crying), you know it don’t take much...I helped my youngest this month, and now I’m suffering for it, because she didn’t pay me back. She said she thought she was going to pay me something, some part of it, and I didn’t get it, so she said tomorrow she’d get me some money, but I’m just kind-of short right now.

Other women mentioned the inability of their children to accept or understand their condition as well. Here Lornah describes how her children could not accept that she was in pain, because she did not react the way they thought she ought to:

No, I’ve gotten no support from my family. They begrudged me the right to go on and live normal and still be sick. They could not handle it. My son and daughter, my son said, after I got cancer the second time, ‘We just can’t picture you in pain.’ They didn’t pick it up because I didn’t show the pain. But, I told them I said I was in pain, and what else do I have to do. When I grew up it was different, we didn’t complain, and we didn’t over-exaggerate, that was part of life. There was a time limit to it, and you just go on. I grew up walking around with fish hooks stuck in me.

Beatrice talks similarly about her “upbringing” as a reason she did not express her pain by crying:

But you know, that was instilled in us, you know, not to cry....I remember crying, and my grandmother sitting me on an old rickety chair in the center of the living room. We didn’t have no furniture, just a couple of chairs, sitting in the middle of that living room with a belt and telling me to shut up. I mean, here I’m crying, and she whips me, ‘saka shut up’. I mean how you going to shut up when you’re getting whipped? You know what, you do! You really do, you do, you learn not to cry, in spite of pain. So maybe, I’ve thought about it, this is it. No tears. Just one time when I combed my hair and my hair fell out, other than that I don’t remember really any tears.

This perspective may be significant in that she may not be able to relate to
people around her who react this way to her illness, and have to alter her relationship with them. Luci illustrates this without a doubt:

I don't want to hear people crying - I don't like all that stuff. It doesn't help me. It might help them, but it sure the hell doesn't help me. I don't need somebody sitting around . . . because what it does, it tells you people are crying and everybody thinks you're dead already. You know? They don't even give you a chance to survive. And that's not fair to do to anybody... Doesn't help anybody to feel sorry for somebody. What I would do, is if I would see somebody in front of me smiling, I would say, 'thanks a lot.' To those others I would say, 'You're waiting for me - I'm going to die, aren't I? You think I'm going to die?' Why don't you just give me a lot of support rather than cry because I'm going to die.

Ada began having problems with her boyfriend before she was diagnosed with cancer. She described her cancer as "accelerating" those problems into a separation. In the next quotation she talks about her own striving for self-reliance as well as her boyfriend "not knowing how to react", which became too much for her at the time of her illness:

I refused to let anybody do anything for me that I wanted to do myself, like as far as the house, and I couldn't keep up the house, I mean, I would try, and that's when I was in and out of reality, I guess, consciousness, and I don't remember too much because of the chemo. But my little boy has always been a really good little boy, and my boyfriend, I mean he was good at the house and stuff, I mean keeping up and helping me in his own little way, but he'd never had to deal with that, being an only child, I think he was kind of, you know, he just didn't know what to do, how to react. So I pretty much wouldn't ask him for help. They wanted to send hospice, the people, and I told them 'no'. Home health, I told them 'No, I don't need them. I'm fine.'

She describes further in the next statement, her boyfriend's inability to accept changes in responsibility upon the advent of her illness:

I didn't want the place to be unhappy for my little boy, his daddy and I were together for almost nine years. So, there was a lot going on, and I just tried spending as much time with my little boy as I could. I mean, cause I was in the hospital so much. Actually that's what hurt me the most was having to leave him-- never knowing, is his dad goofing off somewhere?, you know. Cause he had a tendency to just get up and go off, you know, by himself, at night. And, I'd think, well, if my little boy is there, he's not thinking straight or something, he could get up and go off.

Ada further explains how her boyfriend's denial about her illness was practically a threat to her survival:
The last time they released me from the chemo, before they did, I was kind-of going out of my head then, I guess it was just from all the, you know, reactions of everything, and it was one of the side effects of the chemo and radiation, too. It was just, I mean, it killed everything, so everything is off, you know, all your, everything, you’re whole body is way off. And I guess I was dehydrated and all of that, the electrolytes were all imbalanced. I don’t even really remember being discharged from the hospital. And then there’s little things in and out that I can vaguely remember, but that’s how bad it was, and that stayed like that, it was about a week. Also major diarrhea and throwing up, constant, all day long, couldn’t hold nothing down. Finally, I just made myself get up, cause my boyfriend that I lived with then, my little boy’s dad, he wasn’t very good support for me. I mean, he’d feel sorry in his own way, but he’d go off to himself, and so I didn’t have anyone there. And I finally got myself back into the hospital, to get that straightened out.

Luci sums up her feelings about the reactions of others and the stigma of having cancer:

You know what I felt like? It felt like when I was in foster homes. And when I was in foster homes, any parent that I had - which totaled quite a few in different foster homes - is what it felt like is, it was like there used to be a stigma being a foster child, and being raised. And it scared me so bad, you know. And every time you went to a different foster home, you hoped that you could stay there, so you’d do everything right so you could have some parents, you know? And someone that could love you. You know? So you just hoped - you hoped - that this could happen. Which it didn’t...You know, same exact feeling...because then, I mean, everybody knew I had cancer, so it was like...so everybody, I don’t know, like I had a disease - a disease that maybe somebody was going to catch or something. Which I thought was kind of stupid, but that’s how they reacted; everyone reacted. I didn’t really have any choice...that’s how everybody reacted to me.

Josie’s solution to the problem of being stigmatized was to nurture a relationship with an entirely new group of people in order to remain anonymous and avoid being labeled a “cancer patient.” Here she talks about how and why she switched from the Baptist church, where she had been a long time member, to a Lutheran church where she knew no one:

A Lutheran pastor came to visit me [in the hospital], and I was glad that he came. He didn’t even know who I was. Got my name off the computer, and he said ‘Well, you live, you’re close to my church, why don’t you come visit us,’ and you know what, when I felt better, ‘I’ll come and pay you a visit.’ And he prayed for me, and that’s what I did. I went there between my chemo treatments, so that helped me through. People treated me like I was another human being. They didn’t know, he didn’t tell them (at the church?) Right, and so that way I was able to fit in and forget about what was going on, and just try to get my life back together.
The best way she saw to be treated as a "human being" was to go to an environment where no one knew about her cancer. This is a revealing statement about the power of the stigma the women faced when confronting their cancers. Clearly, their task after being diagnosed had as much to do with gaining independence from this powerful and oppressive label of 'cancer patient,' as did the task involve attending to their physical bodies.

Optimism

Almost all of the women participating in the study expressed the need to be "optimistic," or to be "positive," when discussing or thinking about their illness. This need to be positive or optimistic could be seen as yet another way the women were attempting to break away from the label of the "cancer patient," the "cancer patient" who is supposed to be "morbid and sad" in Lornah's words. That line of reasoning may explain why the other people in the women's lives found it extremely difficult to allow them this freedom.

The individuals, groups and organizations that did not allow the women to look upon their situations in a positive light prompted them to reevaluate their relationships with such persons and organizations. For many women, the need to be "positive" encompassed a need to accept the cancer as a natural, if unwanted, part of themselves that need not be feared. Several of the women attributed the inability of others to let them be positive to their own "fears."

Lornah comments on the people around her:

They are much more afraid than I. And this makes it hard to share, so I take it on myself.

This phenomenon often led the women to pursue relationships with those who seemed to be less "afraid," and gave them positive relief in the form of humor, or escape. For example, Josie explains further why she chose to leave the Baptist
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to do. She describes the support group staff in the hospital that made it difficult for her to choose this option:

They had a couple of nurses, and a support group come up there when I first started chemo, you know, and they're sitting there like this, 'Ohhh, anything you want to talk to me about, you can.' And they kept pushing it, and I was like, I was so sick of these people, its like, 'There's nothing I want to talk to you about, leave me alone.' (yeah) And I'm trying to sleep here. And she'd say, 'You can fill out these papers, and if..'. You know, she would come about four or five different times a day, during the day, and I just took the papers and threw them away finally; it's like, 'I'm not filling these out. I don't feel like it. I don't want to talk, I just want to sleep,' you know what I mean. 'I told you there's nothing I want to say,' which there wasn't, you know. 'I'm cool with this', you know, 'why can't you be?' (yeah, that's really interesting) But, yeah, I guess she was just doing her job, but, cause I guess a lot of people, you know, keep it bottled up, they say, 'oh, you know, I'm fine,' and they're not, maybe they're used to that or something. But, no, when I say, 'no, I'm fine,' I mean it, I'm fine, leave me alone.

Several women talked about being thankful that because of their illness they had become involved in the Talking Circles at the Native American Health Centers. These circles are small groups which meet to discuss general health issues. This group seemed to be more supportive for the women than other support groups. Here Josie illustrates why this is true for her:

That's the good part about it, getting in with the Talking Circle, ah...because no one knows you have cancer or you went through it, and they really don't care, you know, that's what I'm saying (yeah), cause they don't know, they just see you as another branch on the tree, and we have all this love, when we come together.

Again, she believes the option to remain anonymous is important. Mina also mentioned that she began attending a Talking Circle because of her illness. This alleviated some deeply ingrained fears she had around the issue of her cancer:

My uncle. My uncle had cancer, and my cousin, which I call aunt, cause, because I was raised with her and she took care of me, and she died of cancer. All my cousins died of cancer. Five of them.... I keep on thinking I'm going to die with cancer. So, cancer scares me. But, they have talk, at the Indian centers they have a circle, they talk, and I go down there, like about two hours. They talk, and stories...so it helped me a lot when I go down there and be in their class, cause they try to do a lot of things for us Indians.

At least three of the women cited the circles as "positive" environments in which
they could discuss their health issues.

Many of the women also expressed the need to participate in a positive, useful way in society, or in a group. Josie describes a volunteer acting group that became a support for her:

I did a little ah, acting with the [group], and that's some other support group for me. I was with them before I got ill, it started in '92, and so when I was diagnosed with breast cancer, and had the surgery and stuff, this was during the summer, so I went for the retreat in September, I let the director know, that maybe I wouldn't be able to perform because of that experience I went through, but she insisted, 'no, no, no, we still want you in the play, if we have to work around you.' 

Velma found that her new relationship with the Women's Cancer Resource Center is an incredible help to her. Primarily because this relationship allows Velma to become involved with different activities in the community, and leave her illness behind for a few hours. This is something she has not been able to secure from her family relations:

I have to find ways to get, to create the support, other than [my daughters], because they have their lives. I can't expect them to give up their time to help me. My youngest is trying to get an education, and she works too. And I try to help my oldest with my grand-daughter every so often, but I told her that I can't do it very often, cause it's too, I need the time I have for me. And it's too stressful for me to do it, so I don't want to have to. I've taken care of her since she was born. She's nine years old now, she'll be ten. Can't do it no more. At the Women's Cancer Resource Center, they have a program, I have a volunteer that comes every week. They have a program where they have volunteers that spend at least three hours with you once a week, and she comes on Sunday, and spends three hours with me, from two to five. And she helps me sometimes with the house. Most the time we just find fun things to do, because I need to get out of the house. So, we go out. She gets me out. It means a lot to me.

For Luci, "getting out" meant taking up a hobby she had enjoyed in the past. This activity turned out to be a major source of strength for her, as well as a respite from her role as a "cancer patient:"

Once I had settled down with my bowling, I was just, it was the one thing I could do. My husband told me, he said, 'sometimes I don't know how you do it.' I said, 'I'm going to conquer this thing, I don't care what anybody says.' And so I did the bowling.

In conclusion, it was important for many of the women to be optimistic
about their lives with cancer. This need drove them away from certain people and groups in their lives, and, often, toward more supportive relationships. Part of the need to be optimistic manifested as needing to be "in the world," "getting out," "creating," and "being active." As will become obvious in the next section, the need for optimism only increased for the women as they allowed even deeper change to take place in their lives.
Shifting Internal Relationships

This section illustrates changes that the women experienced within themselves. For individual women, these changes manifested as: a change in relationship to her body, a change in the way she viewed herself as a person, or a change in her spiritual beliefs. As will become apparent, these changes were all integrally related to each other, as well as to the changes outlined in the preceding sections. For simplicity’s sake, the findings in this section are divided into two sections, Self, and Spirit. These divisions, at least, should be viewed as reflections of a continuum, and probably more accurately, should be viewed as inseparable aspects of a single process.

Self

One important part of the ‘self’ that the women discussed was the physical self. Nearly all of the women expressed that through the process of their cancer they developed a closer, or more attentive relationship with their body. For most of the women this meant a new respect or appreciation of their body, and greater attention to pain. Ada talks about this in the following quotation:

I pay more attention now to something that hurts different, or something else I feel, than I would have in the beginning. In the beginning, I’d be like ‘Well, it’s not killing me, deal with it,’ and never go to the doctor. But now if something acts up real differently, I mean I’ll let it go for a little while, and try to figure out, well, is it getting better or worse, or is it something...you know.

Beatrice echoes this sentiment when she says:

Now I am more aware. When I hear any little thing wrong, I pay attention. I try to take more care of my body, cause I realize that’s important.

Beatrice decided several years ago to end her career as a nightclub owner, and become a special education teacher. She does not feel that the chronologic
sequence of her illness, and then change in career, are causally related. But it was clear that part of her change in career came out of a desire to increase the health of her body by ceasing her consumption of alcohol. The desire to quit drinking may have been present previously, but the momentum to do so came at a time when the well-being of her body had become a central concern to her:

Right now, I'm finishing up my school so I can be a teacher. (what are you going to teach?) Special education. I was in the nightclub for 24 years—I was the bouncer, the bartender, and the owner! And I did all that, and one day I just said, 'Enough!,' and I got out of it. But that was what I did and I was there, but I don't miss it.

Rose describes a renewed understanding of the importance of taking care of her own body, a sentiment that reverberated through nearly all of the women’s stories:

The one thing that's been a wake-up call is that you just have to take care of yourself (yeah). If you don't take care of yourself, nobody can take care of yourself for you.

Another part of the "self" that many of the women mentioned was their internal image of themselves, including their roles in life, as well as their own strengths and accomplishments. Josie describes how her illness has led her to a new view of herself as a person:

And cancer is like fighting a war, so then I put myself in the category, 'I'm a warrior.' Cause we did have female warriors too. (right) So, if I was living during that time, when we had warriors on our territory, then I would have many eagle feathers. (yeah) Yeah, cause I survived this battle.

She illustrates further how her experience has brought her strength rather than weakness. This attitude in and of itself could be seen as a powerful resistance against the label of 'cancer victim.' She explains,

It made me stronger. I can face any challenge, that's my attitude now. And I don't let people push me up a corner, or you know, treat me any kind of way, cause my attitude now, 'No, wait a minute, you don't know what I've been through,' (right). I can handle this situation, so. Yeah, people tend to worry about the economy now. How they gonna pay they bills, how are you going to pay your rent? That's petty stuff to me. Worry about your body, that's the most important thing. Cause if you don't have a body, how you gonna pay the bills?
In the last part of this quotation she talks about the fact that her "body" has become a more important concern to her than other potential concerns in her life. Lornah makes an almost identical statement describing her new priorities in life:

One thing I learned is how trivial it is to hang yourself up on things that don't matter...its not a pimple or a bee sting to me--how trivial. (What kind of trivial things?) Like people worrying about wages, house, thinking materialistically, where they're going in life. I like to enjoy life as it comes, kick back and see what's there, you know. I may have fifteen more years to live, and I'm going to enjoy it.

However, Lornah's evolution to this point has not been easy. She describes the way she felt initially after her hysterectomy and mastectomy.

I just knew I had nothing anymore. We were taught to have children, and I couldn't blame my husband, even though I had already given him three children, I couldn't condemn him because he couldn't deal with it. I was not complete anymore, not a whole person. Its very wrong for Indians to lose parts of their body.

It was Lornah's renewed spiritual beliefs that allowed her to again bring meaning to her life after such incredible devastation. In the following quote, she describes part of an experience she had during one of the healing ceremonies which brought her to a new understanding of her life, and her illness:

But they [the spirits] started talking to me, I was an eagle's relative and they were calling me High Eagle Woman. The generations that came before us knew what suffering was. They showed me suffering we do not know. They showed me a white seal disease. They said that everyone that came would suffer, and we should stop crying and help ourselves. I saw that we are really very lucky to live in this era, with everything we have.

Ada talks in the next quotation about her renewed appreciation of life following her experience with cancer. She feels that she has a "second chance," and talks of improving the way she spends her time:

Well, I've always been pretty open minded and enjoying life's little pleasures, but now it seems like it's, you know, I figure it's a second chance, you know, make use of it. Better than whatever I was doing before. Because all the time before that, I worked all the time, and when I started getting sick, about a year or so before they diagnosed cancer, I worked all the time. And I guess that's pretty much all I had on my mind, working and things.
Luci spoke also of this new beginning in life, requiring a new and deeper relationship with her own 'self,' and strength:

It takes absolutely everything out of you -- it strips your whole body, your mind. It takes everything out. And when you turn around and then everybody just goes, "Oh, hi! Bye!" You know, everybody takes off. You are wondering, "What the hell did I do this for? Yeah, what did I do this for? For what?" But that's when you have to sort of, take hold of your life and start doing things for yourself and make your -- because you end up taking different things in order to become successful.

She illustrates in the following statement, how she sees herself as "lucky," partially due to the fact that she appreciates what an important role she has played in the training of her doctors:

I think I'm lucky. I'm lucky that I've been so knowledgeable about what my disease is to a lot of doctors, I think. I really do. I pride myself -- I mean, I didn't really want to learn it this way, but, everything that I've done, everything that I've done for the doctors has been -- at Stanford, U.C. Davis -- my doctor, she actually had to go. She had, actually, left...I lost her, but she was great. I know she learned from me. Her name was Dr. Stewart -- I know she learned a lot...The things that I did for the medical world-- it may not be that much--but, it's enough, that I know.

Josie illustrates the new priorities she has in her life in the following observation:

Ah, I believe I have a new life. I see things differently. I see life differently. Life is precious and time is short. That's my belief now. I take time to enjoy life, I take one day at a time. Cause before I was always doing stuff for my daughter, for my job, for my church, whatever was needed, Josie would just do, do, do, and go, go, go, instead of taking time out for myself, and enjoying life. Now I'm enjoying life, life is good, life is fun, its whatever you make of it. And I just take one day at a time, I deal with today, tomorrow I don't worry about that, cause that's borrowing tomorrow troubles.

It is clear from this statement, and others from Josie in this section, that her new feelings about her 'self,' her body, and her spiritual life, are practically inseparable.

**Spirit**

For several of the women, a new spiritual perspective emerged in their lives through the process of interacting with their illness. For several others,
there was a strengthening of a long-held spiritual understanding. In both cases, these women’s spiritual lives increased in importance to them. Many of the spiritual changes that the women experienced have already become evident from previous quotations. This is not surprising due to the fact that rather than being an isolated aspect of their lives, their spiritual beliefs and needs typically permeated all other aspects of their being. Lornah illustrates this point in the following statement:

But the spirits taught me, here I am griping, the best of medicine, the best of education, here I was complaining...that experience took a lot of anger out of me. William, who has had a lot of experiences with the spirits that told me that, now, the way to really heal was to bring back the family, heal the family. But to me, to bring back my family circle was very hard—to go with a man who had beat me unconscious—back to him? And he’s not the one who has to go back. The spirits told me if I want to believe, then I have to totally believe.

Lornah shows how her spiritual relationship was related to her relationship with her ‘self,’ and her “anger,” as well as to her relationship with her medical care, and her family. In addition, she illustrates how struggles in one area were inseparable from other struggles for her, just as her faith was inseparable from her healing.

For Beatrice, illness has changed her beliefs about the sanctity of life, which has consequently manifested as a change in her “self:”

But, I’ll tell you Ginny, the thing that’s changed for me is, I’m not as mean as I used to be! Ohh, I could be mean. And now I see life differently, every life, when I look at every person, every life is just precious. And everyone has their own thing to give to the world. You know, Ginny, its very important to me.

Rose describes how her physical experience has brought her to a realization of her own mortality, and an increased reliance and awareness of her spiritual life:

I thought, you know, you go through periods of time when you think nothing can really happen to you, somehow you can beat it all, no matter whose done something to you in the past, I mean that’s how I got through all the things that my dad did to us as children, all the things that have happened to me, I got through it thinking I can beat this, no matter what it is, I somehow am beyond it, I am above it,
I can get through this, and then to have that happen was like somehow that punched a whole in my armor, so to speak, you know, because I've had nobody to protect me and take care of me, I've had to do this all on my own, it's been between God and I, that's it.

In this final quotation, Josie shares her new view of her cancer as part of a larger plan in her life, her "destiny:"

That was my destiny. That would be my final statement. We all have a road to walk on, we have to do that by ourselves. No one can do that for us, and it was chosen for me, to have cancer.

Many of the women, although perhaps wishing there had been an easier path, echoed her sentiments. They believed that the "road" that was "chosen" for them was long and difficult, but it was their road nonetheless. And they certainly did walk by themselves if no one was there to walk alongside them.

The following chapter presents a short summary of the project and further discusses the findings presented in this chapter. Implications and questions for future research are also discussed.
Chapter Six: Summary and Implications

This study is a qualitative analysis of the experiences of American Indian women with cancer in urban northern California. Due to the size and diversity of the participant group, no generalizations or conclusions about urban American Indian women with cancer can be derived from the findings of this study. However, the findings do present important implications, several of which either support or oppose previous scholarship. The precise research questions addressed by this study were: *What have been the experiences of these women, with cancer?* and subsequently, *What did the women need during the time of their illness?* The answers to these questions were sought through in-depth, semi-structured interviews. The interviews were recorded, transcribed, and then analyzed using a "grounded" method. This method included coding each line of the transcripts, and then searching for categories of codes. This process was repeated several times to reveal prominent themes in the women's experiences. The final emergent themes were the major findings of the project.

Eight women participated in the project. They had heterogeneous tribal backgrounds, as well as varied current involvement with the "Indian community" in their respective urban areas. The women ranged in age from 38 to 68 years old, with an average age of 52.3. The women were all "low income," and all but one received insurance through Medi-Cal. Nearly all received some type of care at the urban Native American Health Clinics. These differences and commonalities brought both strengths and weaknesses to the project.

One finding of the study was that the women's experiences with cancer were particularly marked by shifts in certain relationships in their lives. These
relational shifts fell into three major categories. The first category was a shift in their relationship to the world of medicine, including individuals affiliated with that world, as well as to larger systems of care. The second was a shift in their relationships to the people and groups in their lives, their social world. Last, was a shift in internal relationships, that was a change in a woman’s relationship to herself, or to her spiritual beliefs.

_Implications for Medical Relationships_

The women in the study experienced a shift in their relationship to the world of medicine. The predominant shift for the women was a shift from a paternalistic or “naïve” relationship with conventional medicine and providers, to a self-possessed or “empowered” relationship with those parties. This shift occurred due to several needs that arose for the women during illness that were unmet within the confines of the original relationship. The major needs identified were: the needs for better communication with providers, increased respect from providers, and increased integration of care with other healing systems.

The expressed need for better communication with providers implies that for the women participating, lack of adequate communication with providers is a factor in their avoidance of the medical system in general, and therefore a factor in their late diagnoses of cancer. Poor communication between providers and female patients is a longstanding problem in medical interactions (Ehrenreich, 1978). This problem is also amplified by class and cultural differences between patients and providers. Sociologist Paul Starr states:

...when poor and working-class people encounter [medical] professionals, they often experience difficulties in communication because of differences in linguistic and cultural background. Not sharing the same assumptions, they are more likely to be guarded in their communication and to feel alien and hostile. Many of their
contacts with professionals are involuntary or take place in public institutions, and they do not have the control that private financial means provide. Under these conditions in schools, hospitals, offices, and agencies, individuals from the lower and working classes may comply, if at all, more for reasons of dependence than for reasons of belief. They may simply have few alternatives (Starr, 1982, p. 12).

Several of the women in the study expressed the feeling of having “no alternatives” regarding their medical care. Despite the small participant group of this project, the existence of communication problems as a theme in their experiences suggests that this problem has yet to be addressed by the medical community.

After one extensive literature review of patient satisfaction in general practices, it was found that:

Most consistently identified as being of particular value to patients are interpersonal skills on the part of the practitioner. It is suggested that such techniques should receive wider acknowledgement as a basic element of the practitioners technical repertoire (Lewis, 1994).

This result implies that communication difficulties are far from being isolated findings of this study. One recent review of the literature on doctor-patient communication claims that today “communication can be seen as the main ingredient in medical care (Ong, 1995, p. 903).”

The women participants identified “listening” as a specific element of communication that was sadly lacking. They are not alone in their inability to hold their doctor’s attention. Numerous studies have documented frustrated complaints from patients that their “physicians didn’t listen (Miller, 1994, p. 79).” In the current climate of increasing managed care, “interruptive” technology (pagers, cell phones, etc.), and decreasing time for patient encounters, it seems especially relevant that doctors be more extensively trained to “listen.” For the women in this study “listening” had a therapeutic value above and beyond obvious diagnostic or other values. This is yet another reason to elevate proper listening skills to a higher level of priority in the training of medical providers.
The second need identified was the need for increased respect from providers. The history of disrespect to women, and especially women of color, by medical providers is very long. Indeed, up until the middle of the twentieth century, many doctors still believed women and people of color to be members of un-evolved inferior human species, based on extensive "scientific evidence" in the literature of the time:

Almost all (medical professionals) agreed that existing human races represented different evolutionary stages. A vast body of research—consisting chiefly in measurements of brain weights, head sizes, and facial proportions—"proved"—to no one's great surprise—that if the ethnic groups were ordered in terms of their distance up the ladder of evolution, WASPs would be in the lead, followed by Northern Europeans, Slavs, Jews, Italian, etc., with Negroes trailing in the far rear...everyone must have an assigned place in the natural scheme of things. Attempts to get out of this place are unnatural and in fact diseased. By the eighteen sixties, natural scientists could pinpoint woman's place on the evolutionary ladder with some precision—she was at the level of the Negro. For example, Carl Vogt, a leading European professor of natural history, placed the Negro (male) as follows:

...the grown-up Negro partakes, as regards to his intellectual faculties, of the nature of the child, the female, and the senile White.

(Where this left the Negro female one shudders to think, not to mention the "senile" female of either race.) (Ehrenreich and English, 1978, p. 117).

In addition, there was a pervasive medical belief that women existed solely for the purpose of reproduction.

"The Uterus, it must be remembered," Dr. F. Hollick wrote, "is the controlling organ in the female body, being the most excitable of all, and so intimately connected, by the ramifications of its numerous nerves, with every other part." Professor M. L. Holbrook, addressing a medical society in 1870, observed that it seemed "as if the Almighty, in creating the female sex, had taken the uterus and built up a woman around it." (Emphasis in original) (Ehrenreich and English, 1978, p. 120).

This study documented that related beliefs continue to exist in the minds of some health providers. This has important implications for the prejudices that remain in the medical world. In this study, those prejudices were a factor inspiring the women to change their relationship to the world of medicine. This finding implies that incidents such as those documented in the study could be a
factor contributing to decreased utilization of medical services, and late stage
diagnosis. This is an important finding in light of the fact that recently there have
been several intervention projects launched for American Indian women and all
of them exclusively involve cancer education for the women (Burhansstipanov,
1993).

A third need the women expressed was the need to integrate non-
conventional treatments into their care. To this end, they wanted both the
cooperation and respect of their doctors, and more information about the many
"alternative" treatments. Again, the women were expressing a sentiment with a
historical root reaching far beyond their lifetimes. Before the machine of
conventional professional medicine was established in this country, American
Indian and "female lay healing" were the standards of care.

The tradition of female lay healing flourished in colonial America and the early
republic. Colonial women brought centuries' worth of healing lore with them from
the old countries, knowledge which they carefully revised and adapted to meet
the conditions of the new land. For their knowledge of the available herbs, they
depended ultimately on the Indians, who alone knew the healing powers of the
native plants. The mixing of Indian, African and European lore produced a rich
new tradition of female healing--complex in its knowledge of the plants and the
seasons. Involving not only how to find or grow healing herbs, but how to pick and
dry them, how to administer and mix them, or combine them with the use of

Since the earliest attempts of the conventional medical establishment to
discredit and eliminate "lay healing" practices, there have been countless efforts
to reinstate those practices. One such effort was through the Thomsonian
system, which was started by a poor New Hampshire farmer, Samuel Thomson,
in the 1830s. This system would become for a time, "the main basis of the
working class and feminist alternative to regular medicine."

Thomson's system was little more than a systematization of Mrs. Benton's [a
female lay healer and midwife from whom Thomson had been taught his skills]
combination of herbs and steam, which in turn was derived from Native American
healing lore. But it was a great success with the people Thomson visited, perhaps
because by this time so many people had had a brush with regular medicine.
Thomson could, at this point, have settled down to become a respected local healer, but his medical philosophy involved much more than a set of techniques. His goal was to remove healing from the Market and utterly democratize it; every person should be his or her own healer. To this end he set out to spread his healing system as widely as possible among the American people. In 1822 he first published his entire system as the New Guide to Health, which sold 100,000 copies by 1839 and in the decades that followed he set up hundreds of "Friendly Botanical Societies" in which people met to share information and study the Thomsonian system (Ehrenreich and English, 1978, p. 52-53).

The American Indian women participating in this project expressed sentiments most likely reflecting yet another resurgence of such so-called "popular health movements" that have been found in this country since its inception. The current movement may however, have an "advantage" over its historical relatives. The conventional medical establishment, as well as private industry has now realized that "alternative" or traditional medicine is also a "market" which they could use to cultivate profits. With this market incentive, as well as the incentive to provide more comprehensive care, traditional medicines are now being reexamined. The fact that the women in the study were even partially successful at securing knowledge about other systems of care may reflect this trend. Although a bittersweet victory for traditional healing practices, this "market interest" seems to be increasing integration of "alternative" systems into the medical establishment, and the mainstream culture giving women such as those in this study more access to the information they want.

It remains unclear, however, whether the women in the study were primarily influenced by their own tribal cultural backgrounds, or the growing movement in the larger American culture. In either case, their desires run parallel to the desires of many others in the country. This national interest is illustrated by the coverage of "alternative medicine" in the popular media, the appearance of "alternative" or "holistic" clinics in mainstream health maintenance organizations, and the sales of "alternative therapies" in stores.
across the country. "Alternative medicine" is no longer a fringe movement making sales exclusively in small health food stores. The movement is so large it can hardly be referred to as "alternative"—studies have reported that 40 percent of Americans have used a "complementary or alternative therapy" within the last one year (Durso, 1998, p. 12). People can now buy Golden Seal powder—known as "yellow Indian paint" in colonial America (Ehrenreich, 1978, p. 40)—at Walgreens, get "alternative medicine coverage" from over 25 insurance companies (Durso, 1998, p. 12), and buy Ginseng in vials at gas-stations and convenience stores. Consequently, the findings of this study, if not unique, seem highly relevant. Perhaps the most important implication of the findings is that increased knowledge on the part of medical providers may be helpful, if not necessary, in cultivating more beneficial doctor-patient relationships, and therefore more positive disease outcomes.

**Implications for Social Relationships**

The women participants also experienced significant shifts in their social relationships. The direction of those shifts were variable, but tended to move towards satisfying two identified needs: the need for *independence* and the need for *optimism*.

The need for independence was typified by a need to be considered an individual rather than a generic "cancer victim." At the outset of her inquiry into the nature of the "cancer victim" label, Susan Sontag states the following:

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 of national character. My subject is not physical illness itself but the uses of illness as a figure or metaphor. My point is that illness is not a metaphor, and that the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking. 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. It is toward an elucidation of those metaphors, and a liberation from them, that I dedicate this inquiry (1978, p. 3).

The women in this study described at great length "punitive and sentimental fantasies concocted" and imposed on them because they had cancer. They worked hard and were often successful at revising their personal mythologies about cancer and illness. In the end, however, it was the mythologies of others, which were painfully out of their control, that caused them the most harm.

Sontag further elaborates:

Although the way in which disease mystifies is set against a backdrop of new expectations, the disease itself (once TB, cancer today) arouses thoroughly old-fashioned kinds of dread. Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are the object of practices of decontamination by members of their household, as if cancer, like TB, were an infectious disease. Contact with someone afflicted with a disease regarded as a mysterious malevolency inevitably feels like a trespass; worse, like the violation of a taboo. The very names of such diseases are felt to have a magic power (1978, p. 5-6).

The problem articulated by the women in the study appears to be a pervasive one in Western culture. Whether or not this problem is more severe in urban American Indian populations cannot be speculated from this study. It can be said, however, that this problem exists in the Indian community, as well as in the larger culture, and it is a problem worthy of attention. One of the study participants articulated her impression of the "cancer" problem and the solution when she stated:

It's devastating. It's a real hard word to hear. It really hurts. It really does. I don't care what anybody says about words - it's frightening. It's like the devil himself. It's horrible......going through cancer, because it still has that huge stigma on it. Aaah! Might as well be attacked by a monster or something or get electrocuted or something, because it affects everybody like that......And cancer nowadays has really got to be put out to the public that it's not as bad as it used to be.

Sontag similarly expresses the necessity of changing cancer in the public eye when she states,

As long as a particular disease is treated as an evil, invincible predator, not just a
disease, most people with cancer will indeed be demoralized by learning what
disease they have. The solution is hardly to stop telling cancer patients the truth,
but to rectify the conception of the disease, to de-mythicize it (1978, p. 6-7).

The implications of this project simply reiterate the desperate need for us as a
culture to become educated, and to "de-mythicize" cancer.

The second identified need the women emphasized was optimism. The
women believed it essential for their health to remain optimistic about their
prognosis, as well as to enjoy the remainder of their lives unburdened by
constant "morbid and sad" thoughts about their cancer. This need can be
viewed as a direct rejection of the role of "cancer victim," but it may have other
origins as well. Currently, the developing field of psychoneuroimmunology is
exploring the possibility that thoughts, positive or negative, and emotional
states, can directly influence the immune system. This interest is in addition to a
vast array of "alternative" and traditional systems which have operated under
such beliefs for centuries.

The need to be optimistic could also be a cultural one. One study of
Navajo elders in Arizona found that "speaking or thinking in a negative way"
was regarded by the informants of the study to be something that could directly
cause them harm or death. The informants explained that patients and
providers "should think and speak in a positive way." Speaking negatively was
found to be a violation of the concept of "hozho," the most important concept in
traditional Navajo culture, having to do with harmony, beauty and goodness in
life (Carrese, 1995, p. 826). The origin of the women's need to be optimistic
certainly cannot be determined by this study. However, several implications for
treatment, stemming from the need for optimism, can be made.

The first implication is that while the current structure of most support
groups may be useful for some women, others may need a more "positive" form
of support. This study implies that in addition to talking about their experiences with cancer, some women need to be involved in creative activities during the time of their illness. Talking Circles, which are support and education groups run by the Native American Health Centers, seem to be structured in a way that was helpful to most of the women in this study. These groups do sit in circles and talk, but they also have lunches, go on field trips to museums, and watch films. This study suggests that these groups could be explored as more “positive” models.

The fact that the community clinics (urban Native American Health Centers) most closely involved with the target population were the closest to providing an “ideal support group” for the population (the women) also has important implications. The community clinics were apparently most in-tune to the needs of the urban population which they served. This is important information to document in light of the long-term interest of much of the medical establishment in moving away from community clinics and toward large institutional care.

Implications for Internal Relationships

This study revealed that many of the women participants underwent a shift in their relationships to their “self” or to their “spiritual world” as a result of their illness. Most of the women reevaluated their feelings about their body, many about how they spent their time, and what they wanted to accomplish in life. Several discussed the role that “spirits” and “God” played in their lives. The women developed an understanding of their illness that supports the conclusion of Audre Lourde:

Breast cancer, with its mortal awareness and the amputation which it entails, can still be a gateway, however cruelly won, into the tapping and expansion of my own
power and knowing (1980, p. 53-54).

All of the women in the study described some increase in "power" or "knowing" due to the experience of their illness. Some analysts may conclude that this is due to "romanticization" of their illnesses. From the feminist perspective, as described in Chapter Three, this analysis seems unjustly dismissive of the women's descriptions of their experiences. There is still, however, an important point to be made about "romanticization" in the current climate of the stereotyped "cancer patient." Sontag succinctly offers her definition of the "romantic view" when she states:

The romantic view is that illness exacerbates consciousness. (1978, p. 35)

She exposes the implicit danger posed by believing that illness leads to raised consciousness. Renowned paleontologist Stephen Jay Gould has also been outspoken about this:

What are you supposed to learn? Are you supposed to learn something about your psyche? It's just romanticism to look back at something like that and try to find a good side to it (Barasch, 1993, p. 48).

However, the women involved in this study imply that for some, for whatever reason, illness can inspire transformation. Marc Barasch discusses this possibility:

To speak of the spiritual implications of disease raises some justifiably stiff hackles. Illness is an attack on the body by heredity, a virus, a toxin, an oncogene....Still the interplay of illness, healing, and consciousness has been observed throughout the history of medicine....The earliest doctors knew that the relationship between patient and healer is charged psychic space. Illness is a forced descent not only into the body, but into the self. The founders of Western medicine, the physician-priests of the Asklepians at Epidaurus and Kos, made the transformation of both psyche and soma the very basis of their art. Healers in traditional cultures were not only physicians but psychologists, masters of ritual, social mediators, spiritual mentors, and often survivors of illness themselves--were doctors of both body and soul. The Healing Buddha, the Asian equivalent of Asklepius as the progenitor of physicians, is said to have devoted himself to "aiding beings to change their negative patterns. He is especially concerned with prompting beings to a great awakening, a momentous turning point" (1993, pp. 48, 161).
The women in this study seem to be calling for a new view of illness which would allow them the freedom to make what they want of their condition—allowing cancer to be both dreadful and spiritual, and an experience as unique as their individual lives. In searching for this ideal, the women developed a new way of interpreting and experiencing illness.

This new approach to illness is remarkably similar to what Canadian sociologist Arthur Frank has described as the "post-modern experience of illness." This is opposed to the "modern" experience of illness, which he describes below.

The modern experience of illness begins when popular experience is overtaken by technical expertise, including complex organizations of treatment...The story of illness that trumps all others in the modern period is the medical narrative. The story told by the physician becomes the one against which others are ultimately judged true or false, useful or not (1995, p. 5).

This "modern" experience of illness describes the initial "naive" or paternalistic medical relationships of the women in the study. In further describing the "modernist" experience of illness, Frank discusses the "sick role" concept crafted originally by Talcot Parsons in the 1950s. He states:

Parson's observation, made in about 1950, [was] that a core social expectation of being sick is surrendering oneself to the care of a physician. I understand this obligation of seeking medical care as a narrative surrender and mark it as the central moment in modernist illness experience. The ill person not only agrees to follow physical regimens that are prescribed; she also agrees, tacitly but with no less implication, to tell her story in medical terms. "How are you?" now requires that personal feeling be contextualized within a secondhand medical report. The physician becomes the spokesperson for the disease, and the ill person's stories come to depend heavily on repetition of what the physician has said (1995, p. 5-6).

This "narrative surrender" describes the starting points of the women in the study quite accurately. Upon their original cancer diagnoses, all of the women surrendered unquestioningly to the words of the doctors. As previously discussed, each woman's relationship with medicine gradually changed to one
controlled as much or more by her than by any involved providers. Their final stories bear a remarkable likeness to what Frank designates the “post-modern experience of illness.” He states:

In the Modern period the medical story has pride of place. Other stories become, as non-medical healers are called, “alternative,” meaning secondary. The postmodern divide is crossed when people’s own stories are no longer told as secondary but have their own primary importance. Illness elicits more than fitting the body into traditional community expectations or surrendering the body to professional medicine, though both community traditions and professional medicine remain. Postmodern illness is an experience, a reflection on body, self, and the destination that life’s map leads to (1995, p. 7).

This statement reveals another important parallel between Frank’s “post-modern experience of illness” and the women’s changing relationships. The women ceased viewing alternative healers as “secondary” at precisely the same time they ceased to see the personal side of their illness story as secondary. This point is relevant in that it illustrates how medicine may change as marginalized individuals begin to acquire more power in their relationship to the conventional medical system.

In the preceding passage, Frank’s description of the post-modern illness experience includes the “community” as well as “professional medicine.” These are the two levels which the women in the study experienced important changes as well. Reflecting on the “destination that life’s map leads to” was found in the study as a shift in relation to the “self” and to the “spiritual.” Frank’s theoretical framework appears to be a very useful structure with which to view the findings of this study.

The shifting landscape described by the women in the study remains largely unrecognized by conventional medicine. Frank describes:

The scope of modernist medicine—defined in practices ranging from medical school curricula to billing categories—does not include helping patients learn to think differently about their post-illness worlds and construct new relationships to those worlds (1995, p. 8).
Besides acknowledging the shifting relationships associated with illness, this passage provides a framework for the women’s expressed need to have more attention focused on their present lives. The poet Audre Lourde, who had her own experience with breast cancer, reiterates this sentiment:

We must learn to count the living with that same particular attention with which we number the dead (1980, p. 54).

Both Lourde and Frank, as well as the women in the study, seem to be calling for new means to help those who are “sick” live full lives.

Frank’s description of the “post-colonial” experience of illness is also particularly relevant to this study:

The postmodernity [of illness] is more than a self-consciousness that has not been routinely available to the ill. Many feel a need to claim [this] in an active voice. Those who work to express this voice are not only postmodern but, more specifically, post-colonial in their construction of self. Just as political and economic colonialism took over geographic areas, modernist medicine claimed the body of its patient as its territory, at least for the duration of the treatment (1995, p. 10).

Through the very act of participating in this study, the women have expressed their need to have an “active voice.” Although a generalization cannot be made here about urban American Indian women, the idea that the American Indian women in the study exhibited a “post-colonial consciousness” is quite interesting. The framework is perhaps especially well-suited to this study group due to the multiple levels of colonization the women may have had to transcend before reaching the “post-colonial consciousness.”

The following passage further describes this concept of “post-colonial consciousness” as related to “modernist” medicine and the “post-modern experience of illness.”

Colonization was central to the achievement of modernist medicine. Claudine Herzlich and Janine Pierret describe the “sick person” emerging as a recognizable social type in the early modern period, during the eighteenth century. The condition necessary for the emergence of this type was that “the diversity of suffering be reduced by a unifying general view, which is precisely that of clinical
medicine.” This reducing of the particular to the general provided for scientific achievements, but the clinical reduction created a benevolent form of colonialism. The ill person who plays out Parsons’s sick role accepts having the particularity of his individual suffering reduced to medicine’s general view. Modernity did not question this reduction because its benefits were immediate and its cost was not yet apparent. The colonization of experience was judged worth the cure, or the attempted cure. But illnesses have shifted from the acute to the chronic, and self-awareness has shifted. The post-colonial ill person, living with illness for the long term, wants her own suffering recognized in its individual particularity; “reclaiming” is the relevant postmodern phrase (Frank, 1995, p. 10-11).

One of the main needs identified by the women in the study was “independence,” especially from categorical labels. The women fought having their “individual suffering reduced to medicine’s general view.” They also recognized that their illnesses were their’s for life, in essence that their conditions were chronic. Thus, the women of this study are much more appropriately represented by Frank’s “post-modern” model than by the widely used “sick role” model proposed by Parsons.

Before concluding, a brief mention of the astounding language that has evolved in the distinct processes of analyzing and contextualizing this project is relevant. By juxtaposing the findings of the study with Frank’s work, the image appears of American Indian women struggling for their “independence” after having their bodies “colonized.” They engage in this struggle by “reclaiming lost territory,” which eventually leads to a “post-colonial consciousness.” Few details need be provided to see the parallel with the historical struggle of American Indians in this country. Perhaps the women in the study confronted this struggle with a vault of ancestral wisdom of which even they were unaware. To delve into analysis of this “coincidental” language is beyond the scope of this study, but the coincidence is a fascinating occurrence nonetheless. It may be a future topic for socio-psycho-cultural inquiry. Other directions of future research prompted by the present study are presented below.
Conclusions

This study raises numerous questions that could prove to be fruitful areas for further research. First, regarding communication: What precise factors facilitate successful or unsuccessful communication between urban American Indian women and their providers? This study pointed to a need for more straightforward, honest discussion and better listening by providers. Follow-up questions would be: Are these the only factors leading to unsuccessful communication, or are there other factors involved as well? Are these problems more prevalent in provider's communicating with American Indian women, or women with cancer, or is this a problem in other medical interactions as well? The answers to these questions are important to know in the future, in order to improve doctor-patient communication.

Several related questions were raised as well: Are male providers less effective communicators? If this assessment is in fact the case, how can the problem be addressed? Should male students receive additional training in communication? Is their communication problem limited to female patients? Is this a problem with American Indian women that is not as prevalent in the larger patient population? The answers to these questions could provide even more solutions to the problem of miscommunication implied by this study.

A final question concerning communication skills is: Why is it so hard for providers to listen? How can providers enhance "listening" skills? These are both complex questions with answers that will require a great deal more investigation. However, if the administration of medical services is to be effective, the answers to these questions are essential.

Another set of questions raised regarded the "attitudes" or prejudices of providers. The answers to these questions are important to discover because of
the inhibitory effects provider attitudes may have on successful patient care. One question raised was: *What are the current attitudes of medical providers about “alternative” and traditional healing systems?* How are these attitudes affecting patients and their care? This study suggests that this problem exists among the patient population of American Indian women. Is the problem worse for American Indian women, or is this a problem affecting more and more people as “alternative” medicine has become “mainstream?”

Another question regarding provider attitudes that was raised by this study is: *What are the current attitudes of male providers toward their female patients?* What is the extent of harmful prejudice based on gender in the medical world? How are these prejudices hindering care? It is regrettable that these questions still face the medical world at the end of the twentieth century; however, for care to improve, the answers must be sought.

One problem that was not mentioned by most of the women in the study was racism. I do not know if the women did not mention racial discrimination because they did not experience it, or because they were hesitant to disclose this information to me because of my racial appearance. Another possibility is that the women in this study experienced less racism due to their utilization of the Native American Clinics, which are staffed with providers committed to the care of American Indian people. Perhaps the women experienced racial discrimination as sexual discrimination—possibly because of “non-verbal” racial discrimination. Or perhaps racism is less prevalent in the twentieth-century medical world than sexism. Whatever the case, provider attitudes about race would be an interesting area to explore in the interest of improving care.

Other “attitudes” that may provide important information upon systematic analysis are the larger cultural attitudes about cancer. *What do American*
Indians, and Americans in general, think about cancer? How much are these attitudes based on currently known “facts” about cancer? How do these attitudes affect their treatment of loved-ones, friends, and community members who are diagnosed with cancer? The most important follow-up question to this line of inquiry is: How can public health educators work toward eliminating harmful and incorrect attitudes?

Another question raised directly by this study is: What are the attitudes of American Indian women regarding support groups? An interesting project would be to document utilization patterns of support groups by American Indian women and pose the question: How can groups be fashioned to be most effective for these women? Are the attitudes in this study unique to only the study participants, to American Indian women on a larger scale, or to women with cancer on an even larger scale?

A final question raised by this study is: What else could be done to enhance the daily lives of those living with cancer? The women in this study strove valiantly to maintain creativity, love, comfort, security, humor, connection, and productivity in their daily lives after being diagnosed with cancer. Clearly an individual human being cannot secure all of these needs without the help of others. The needs of those living with cancer must be documented, and creative solutions must be designed to address those needs. Solutions that have been designed for those living with HIV and AIDS may provide creative answers, as these diseases have undergone similar transitions from being once viewed as imminent death sentences to now being more accepted as chronic conditions. Many AIDS patients have experienced the “dilemma of survival” that the women described in this study. There are now several organizations working to address the needs of those that will be living indefinitely with AIDS.
They could be useful models to assist those living with cancer as well.

In summary, the women participating in this project experienced numerous layers of unmet need during their time of illnesses. These particular women adapted and found new ways to secure many of their physical and emotional needs. Although their growth is a tribute to their personal strength and resilience, more needs to be done to make the experience of cancer, with all its psychological and physical implications, a less chaotic experience for American Indian women, as well as for others confronting similar circumstances in American society.
References


Appendix A: Potential Interview Questions

As discussed in Chapter Three, the interviews with the women were loosely structured. The questions below were used primarily as tools to embark upon more detailed discussions about the issues raised. Some of the questions below were derived prior to any interviews, but many of them were added as issues were raised during the interview process. The questions are organized into sections pertaining to the periods surrounding diagnosis, treatment, and then the period from the end of treatment to the present. Many of the interviews roughly followed this chronology, but the organization here is for the reader. Except for the asking of the first question, I did not attempt to follow this sequence during the interviews.

_Diagnosis_

Can you tell me what happened when you were diagnosed with cancer?

How did you feel?

Where were you going for medical care?

Were you satisfied with your treatment there?

What did the diagnosis mean to you? What did the word “cancer” mean to you?

How did you think it would affect your life?

Who did you tell about the diagnosis? Friends? Spouse? Children?

Were you able to talk to anyone about it?

Were you afraid of other people’s reactions (i.e., in your family or community)?

Were these reactions what you thought they would be?

Had you ever known of anyone else who had had cancer?
Had you ever heard that Indians don't get cancer?

Did you see yourself any differently after the diagnosis?

Did you feel that there was someone to blame for the diagnosis? Did you blame yourself?

**Treatment**

How difficult or easy was it for you to follow through with treatment after your diagnosis?

How did you feel, in general, during this period?

Did you get treatment from anyone else besides a western doctor?

Do you feel you had adequate support during your treatment period?

Were you involved in any support groups?

If so, was this helpful to you?

Were there any particularly hard times for you?

Did the diagnosis affect your personal relationships?

Did others treat you differently?

**Present**

Has this experience changed you? Your life?

Has the experience changed the way you think about your body?

Do you think about the experience often?

Looking back, what do you feel was the most difficult part for you?

What do you think could have helped you move more smoothly through those difficulties?
Appendix B: Demographic Data

Age

Age Range: 38 - 68 years old
Average Age: 52.3 years old.
Individual Ages: 38, 48, 49, 50, 54, 55, 56, 68

Type of Cancer

Breast: 4
Cervical: 4
Cervical (in-situ): 1
Colon: 1

Note: One woman had both cervical and breast cancer, and one woman had both breast and colon cancer. This is why the above total adds up to ten rather than eight.

Place of Residence

Oakland: 4
San Jose: 1
Sacramento: 1
Union City: 1
Pittsburg: 1

Living Situation

2 of the women live alone
2 share houses with their husbands from whom they are separated
1 lives with her husband (with whom she reunited after years of separation)
1 lives with her teenage daughter
1 lives with her adult daughter, her grandchild and her sister
1 lives with four of her children, her mother, and her grandmother

Employment / Financial Situation

7 of the women were unemployed at the time of the interview
1 woman worked as an assistant at a veterinary clinic and a pet-sitter

All of the women were “low-income”
Health Insurance

6 of the women had Medi-Cal / Medicaid
1 had Medicare
1 had private insurance through her employer

Tribal Affiliation

The women identified as:

Apache
Canadian Indian
Cherokee
Chickasaw
Choctaw / Chickasaw
Quileute
Sioux
Wylacki