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UNIVERSITY OF ALBERTA

WOMEN'S EXPERIENCE OF SURVIVING INVASIVE CERVICAL CANCER: MAINTAINING THE SELF

BY

KATHERINE MARIE LEONARD

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE
OF DOCTOR OF PHILOSOPHY
IN
COUNSELLING PSYCHOLOGY
DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA
SPRING 1990

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Date:....1990 JAN 08.......

Dedication

I dedicate this work to my mother and father.

Abstract

The purpose of this study was to generate substantive theory about the processes which account for the present experience of women surviving invasive cervical cancer as described by these women five to ten years after completion of treatment.

The ten informants came from a population of women who have survived invasive cervical cancer and have remained disease free since treatment. The data were analyzed according to the comparative analysis method of grounded theory.

Experience of cancer had long term effects on the lives of the women in the study, especially on their sense of self. The impact on their self-concepts unfolded over time and involved a process with identifiable phases called maintaining the self.

Even though the intended focus was on the post treatment period, the women contributed the most detailed information about the time of diagnosis and treatment. The moment of hearing the diagnosis had a major psychological effect on the women in this study. Their sense of self was challenged by their new identity as a cancer patient. They felt vulnerable and uncertain about the future. It was clear that even ten years later these events had an impact on how they viewed that experience and how they viewed their current lives.

The effects of the cancer experience involved interaction between the three contexts in which the events took place: self, social and medical systems. The self is defined here as an intrapsychic framework into which new experiences are integrated. The self is both stable and developing and is influenced by social interaction.

In order to adapt in a crisis situation, these women needed to make sense of their situation, to regain a sense of control and to enhance their self-esteem. These are all aspects of maintaining the self. The experience of having cancer was a challenge to their sense of self that they had to meet. For some of them it led to a better organization of self in the sense of changed priorities and greater appreciation of life.

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First, I want to thank the ten women who participated in the study. They were willing to share their stories in order to help other who must take a similar journey. Many thanks go to the staff of the cancer clinic and the many patients who inspired and contributed to this research study.

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Chapter I: INTRODUCTION

As more and more people survive cancer, research in psychosocial oncology logically is focusing increasingly on the needs and the quality of life of the survivors. However, in their review of research concerning survivors of cancer, Fobair and Mages point out that "there is surprisingly little documentation about the quality of life in 'cured' or long surviving cancer patients" (1981, p. 285).

A review of the literature concerning long term survivors of cancer indicated that most of the studies were done of mixed populations of survivors. The results of these studies provided broad generalizations with some suggestions that age, gender and cancer site might be sources of variation that were masked by the breadth of the samples. Therefore, in the design of this study, it was decided that the focus should be on a population of survivors of one site of cancer which is gender specific and usually occurs in adults: women who have survived invasive cervical cancer.

Literature on psychosocial issues and gynecological cancer covers the experience of women from before diagnosis (retrospectively) through treatment to two years after treatment. Most of these studies focus on specific variables such as level of anxiety before and after treatment or level of sexual functioning. There have been no published studies of the experience of invasive cervical cancer survivors more than five years after treatment. Therefore, the present research is focused on the cancer experience of these women and on their current quality of life. Andersen and Hacker (1983b) proposed that the need for improved quality of life for survivors of gynecological cancer is an important rationale for research:

> With advances in treatment, intervention for many women will be curative and more will be living with permanent body changes. The focus of these women needs to shift from staying alive to living (p. 218).

Since little was known about long term survivors of gynecological cancer, a "discovery-oriented" approach was chosen for the research design rather than a hypothesis testing approach. Mahrer (1988) explains that the basis for discovery-oriented research is:

> the intention to learn more; to be surprised; to find out what one does not already expect, predict, or hypothesize; to answer a question whose answer provides something one wants to know but might not have expected, predicted, or hypothesized.

The particular approach used in this study was a grounded theory model developed by Glaser and Strauss (1967) and further by Glaser (1978). The model will be described in detail in Chapter III.

The purpose of the present study was to generate substantive theory about the processes which account for the present experience of ten women surviving invasive cervical cancer as described by these women seven to ten years after completion of treatment. A retrospective study was appropriate because the focus of the study was on a psychosocial process by which these women understand at the present time their experience of having had cancer.

The Quality of Life Question

The experience of cancer has the potential to alter the patients' quality of life. In a study by Fobair and Mages (1981), patients reported that

> they had been changed by the experience of cancer and had developed new attitudes towards time, mortality, work, relationships, and their priorities in life (p.291).

Further research is needed to extend our understanding of what patients consider to be crucial not only to their survival but to the quality of their lives.

Although the phrase "quality of life" occurs in the literature with increasing frequency over the last thirty years, a clear definition is still "problematic." Flanagan (1982) cited a number of studies that equate quality of life with social indicators or subjective satisfaction with social and personal aspects of life. Padilla and Grant (1985) simply defined quality of life as "that which makes life worth living." They concluded that psychological well-being is the factor most predictive of quality of life and that perceived quality of life is mediated by cognitive processes such as self-esteem and perceived control over health. Ferrans and Powers (1985) suggested that satisfaction interacts with the importance the individual attaches to each dimension of quality of life. In this research the definition of quality of life is a subjective evaluation of what makes life worth living. Therefore the individual's own criteria for and evaluation of her quality of life defined quality of life for that individual.

Clinical Observations Related to the Study:

The focus of study began with several recurring clinical observations of recovered cancer patients. The first observation is that some cancer patients have taken the opportunity to reassess their behavior and attitudes and to develop more satisfying life styles. Others appear to have physically recovered but face the future with suspicion. They may be quite depressed and feel that their 'death sentence' has only been delayed. One cannot help but ask, "Why is it that some survivors of cancer, and not others, experience recovery from illness as "a new lease on life?"

The second observation is that patients attach meanings to their situation and functioning that go beyond the medical definitions. A patient who has little actual dysfunction may be depressed because the area of dysfunction is essential to the identity and self-worth of that individual. Another patient may have many dysfunctions but will continue to recognize an ability to make a valuable contribution in some area of life and retain a sense of self-worth.

Finally, clinicians notice that patients talk about very basic concerns in regard to their health care such as trust, fear, dependency, control, support and hope. These issues are also fundamental to human development. These observations led the researcher to consider the question of quality of life from a developmental perspective. Perhaps, quality of life is not a given set of circumstances but something that is developed and maintained over time.

The quality of life of cancer patients would appear to be related to the ability to integrate their experience into their ongoing lives. Mages and Mendelsohn (1979) found in their research that effects of cancer "unfold over a long period of time and, consequently, should be studied in a developmental perspective" (p.256). They suggested that the personal changes produced by the cancer experience need to be viewed in

> the context of the individual's life stage and previous history. The psychological developments at any given point in the process are integrated around the patient's need to adapt to the issues imposed by the concrete realities of the illness. The nature and effectiveness of the adaptation are determined by the patient's personal characteristics and social milieu (p.257).

In considering quality of life from a developmental perspective, the researcher, following the conventions of qualitative research, first considered existing models of human development and decided that the psychosocial stages of Erik Erikson reflected the issues with which patients were concerned. From Erikson's perspective, the quality of life experienced by adults is theoretically a function of the success with which they have completed the psychosocial tasks appropriate to their age or stage in life. However, it was decided to set aside such hypotheses in approaching the interviews in order "to find out what one does not already expect, predict, or hypothesize" (Mahrer, p. 697). No specific model or theory other than that providing the research methodology was applied.

The Research Question

The research question was twofold. The first part of the question concerned the kind of quality of life experienced by the survivors. The second part of the question concerned the way in which they achieved their current quality of life.

Although the focus of the inquiry was set out at the beginning of each interview as the women's experiences 7 to 10 years after cancer, they were free to focus on any aspect of the cancer experience and their survival. The majority of the women who participated chose to begin their narratives with the moment they received the diagnosis of cancer. It was clear that events surrounding the diagnosis and the subsequent treatment had left an indelible mark on their lives and must be taken into consideration in understanding their current experience of quality of life.

What emerged from the analysis of the narratives was not so much information about what makes life worth living for long term survivors, but a fundamental process whereby they establish and maintain their quality of life in the face of a health crisis and continue to maintain their quality of life in the future. Because quality of life appears to be subjectively defined and closely tied to self-concept and self-esteem, the process that emerged from this study has been named "maintaining the self". This basic psychosocial process will be described in detail in Chapters V and VI.

After the data were analyzed and the process of "maintaining the self" began to be outlined, the emergent theory was compared with existing theories about coping with life threatening crises and about maintaining self-concept and self-esteem. The discussion of these relevant theories will be presented in Chapter VII. Chapter VIII will conclude with implications of the study.

Chapter II: REVIEW OF LITERATURE

This chapter gives an overview of research in the areas of the psychosocial impact of gynecological cancer and of long term survivors of cancer. In grounded theory studies, an exhaustive review does not precede data collection in order to avoid prejudging the data. A secondary review of literature followed data collection and will be discussed later.

Impact of Gynecological Cancer and Treatment

This section reviews the literature pertaining to the psychosocial impact of gynecological cancer. After an overview of the medical aspects of cervical cancer, the review of research literature will focus on: 1) the impact of gynecological cancer on sexual functioning; 2)the impact of gynecological cancer on psychosocial functioning; 3)adjustment to gynecological cancer over time.

Overview of Cervical Cancer

For the year 1986 in Alberta, cervical cancer accounted for 3% of new malignancies in women and 24% of all gynecological cancers (Alberta Cancer Registry: percentages exclude cervical cancer in situ). Since the development of the Papanicolaou (Pap) smear most cervical cancer is detected in the preinvasive stage and can be eradicated before it becomes life threatening. The preinvasive stage cancers are referred to as cervical intraepithelial neoplasia (CIN) or in situ. Squamous cell carcinoma accounts for almost 90% of cervical cancers. Adenocarcinoma, mixed squamous/adenocarcinomas, and sarcomas account for the rest (Andersen & Anderson, 1986).

Invasive means that the cancer cells have grown in depth beyond the epithelial layer of tissue. When cancer cells invade the deeper layers of tissue, they gain access to the lymphatic system and can spread to other tissues. Even small invasive cancers are serious because they can spread to distant organs (metastasize) and can lead to death.

In Alberta in 1986, carcinoma in situ was diagnosed in a higher proportion of younger women than invasive cervical cancer. Sixty-nine percent of the women diagnosed with cervical cancer in situ were under the age of 35 and 90% were under age 45. Twenty-four percent of the women diagnosed with invasive cervical cancer were under the age of 35 and 52% were under the age of 45 (Alberta Cancer Registry). In the past two decades increasing numbers of both in situ and invasive disease have been found among women in their teens and early twenties. The highest risk for squamous cell carcinoma exists in women who began sexual intercourse before age 17, and the risk increases with multiple partners. The main risk factor appears to be exposure of an immature cervix to a venereally transmitted carcinogen. Current research suggests a virus although cofactors are likely to exist (diSaia & Creasman, 1981, Levy, 1985, Starreveld, Romanowski, Hill, Koch & Pearce, 1983).

Preinvasive cancers are asymptomatic. In later stage cancers watery discharge and bleeding especially after sexual intercourse signal that something is wrong. Pain is not usually present until a more advanced stage of disease.

Preinvasive cancers can be treated with cone biopsy, cryosurgery, laser treatment or hysterectomy. Invasive cancers are treated with radiation, sometimes in combination with surgery depending on the extent of spread of the disease. Very early invasive lesions can be treated by hysterectomy. Invasive disease is staged according to the extent of the disease. In stage I, cervical carcinoma is confined to the uterus. In stage II, the cancer has invaded beyond the uterus but not to the pelvic wall or lower third of the vagina. In stage III the cervical carcinoma has extended to the pelvic wall and/or involves the lower third of the vagina and/or causes kidney dysfunction. Stage IV cervical carcinoma has invaded the mucosa of the bladder or rectum and /or extends beyond the true pelvis (Hermanek & Sobin, 1987, pp. 105-106). The earlier the stage the more likely that treatment will eradicate the cancer (diSaia & Creasman, 1981).

Impact of Gynecological Cancer on Sexual Functioning

The largest area of research on gynecological cancer has been on the impact on sexual functioning. The fact that these cancers affect female genitalia and disrupt sexual activity would make this a major area of concern in psychosocial adjustment.

Andersen and Hacker (1983a) looked at areas for psychosocial assessment of sexual functioning. They also suggested a number of measures such as the DSFI, the Sexual Interaction Inventory (SII), and the Sex Anxiety Inventory (SAI) to assess three major variables:

1. Sexual repertoire and frequency of sexual activities (previous and current).
2. Emotional, attitudinal, and cognitive components of sexual activity (arousal, pleasure, satisfaction, anxiety).
3. Sexual identity and self concept (knowledge, ideal vs. real, body image, sex role).

In 1986 Andersen presented an assessment model that closely follows Masters and Johnson's description of the phases of the sexual response cycle: desire (added later), excitement, orgasm and resolution. Andersen suggested that, in addition to the variables mentioned above, "the presence of a healthy interested partner" may have more importance in determining continuing female sexual activity than age. She also suggested that female cancer patients experience a number of changes that will indirectly affect their sexual functioning: 1)medical outcome (change in health status, direct treatment effects); 2)somatization (increased focus on monitoring bodily changes); 3)information on sexual functioning post treatment; 4)affective disruptions (anxiety and depression); 5)reordered priorities (in response to life threat).

In the same article Andersen presented a study of 41 women recently diagnosed with early stage cervical or endometrial cancer and 41 women without gynecological distress. The first group of women were asked to provide data concerning their levels of sexual activities and responsiveness prior to and after onset of cancer symptoms. Their answers were then compared to those of the matched control group. The researchers found that the cancer patients experienced a drop in sexual activity and lower levels of responsiveness after the onset of symptoms. 56% of the cancer patients (after onset) experienced inhibited desire (compared to 17% of the healthy controls). 49% experienced inhibited excitement (7% of the controls). 37% experienced inhibited orgasm (10% of the controls). 37% experienced dyspareunia (0% of the controls). It was frequently the change in sexual functioning that led the women to seek medical attention.

Andersen and Jochimsen (1985) presented a study comparing 16 women with breast cancer, 16 women with gynecological cancer and 16 healthy women. The women with cancer had lower arousability scores and lower frequency of sexual activity than the healthy women. The gynecological cancer patients scored much lower on the body image scale than either other group. Eighty-two percent of the women with gynecological cancer reported poorer body image evaluation in contrast to thirty one per cent of the women with breast cancer and thirty-eight per cent of the healthy women. In the post treatment follow up (more than six months after), they found that sexual behavior or response cycle deficits had not improved over time.

In summary the variables explored included both cognitive and behavior aspects of sexual functioning. The women with gynecological cancers experienced a poorer body image although the visible physical consequences are usually less than in the case of breast cancer. Further the disruptions in sexual functioning appear to be long lasting although the studies only focused on the time before diagnosis, during and up to six months after treatment.

It is understandable that considerable research in gynecological cancer has focussed on sexual functioning, given that short and long term effects on genitalia and sexual behavior are the most observable (reportable) data that can be collected from women's experience with these cancers. As well, these effects are consequences particular to surviving genital cancer. Now it is necessary to return to the women themselves and find out how sexuality fits into their whole experience of surviving and what other issues are important to them in the long term.

Impact of Treatment on Psychosocial Functioning

Mishel, Hostetter, King & Graham (1984) studied 54 women during the interval between diagnosis and treatment for gynecological cancer. They looked at the relationship between uncertainty (inability to evaluate or make predictions), optimism, severity of illness and control over physical function (number of months since last hospitalization) and psychosocial adjustment. They found that uncertainty accounted for 25% of the variance in optimism. They conclude that:

> Gynecological cancer patients who are unsure about the state of their illness and view the treatment as too complex to understand, have less confidence in their physicians and the health care system, feel that their family communications are strained, and family members are less available to help them. As their uncertainty increases, they decrease participating in leisure and social activities (p. 296).

On the other hand the researchers noted that when the women evaluated the impact of the cancer diagnosis on their lives, even if the events were appraised as life-threatening, their responses were less problematic if they were able to determine the meaningfulness of events. They note that:

> When the patient has a clear understanding of the situation, she can activate coping resources. With uncertainty, coping is impeded and activity blocked, resulting in a higher level of stress (p. 298).

Several studies have been done on effects of treatment on psychosocial functioning and comparison between the major treatments: radiation therapy and radical hysterectomy. Both treatments produce stress. Andersen, Karlsson, Anderson and Tewfik (1984) measured anxiety in women diagnosed with gynecological cancer before, during and after internal radiotherapy treatment. They noted that anxiety levels increased in anticipation of treatment and remained high afterwards. Women who had a second treatment experienced high levels of anxiety the second time as well. Women with low levels of anxiety pre-treatment experienced considerable disruption post-treatment.

Sewell and Edwards (1980) studied 46 women with gynecological cancer at least six months post-surgery by either Wertheim's hysterectomy, vulvectomy, or exenteration, all of which affect the vaginal canal and coital functioning). Significant negative differences were found post-surgery in body image, sexual relations and frequency of sex for all three groups. There were no significant differences between the groups on self-esteem, general well-being, locus of control, and social adjustment. "Comparison with available local norms did reveal significantly lower social adjustment for the group as a whole" (p. 37). The authors speculated that patients pull together effective coping strategies over short term periods to re-establish their sense of well-being. They used Bachman's self-esteem scale, Weissman's social adjustment scale, Rotter's locus of control, Fisher and

Cleveland's body image scale, and a general well-being scale.

Seibel, Freeman and Graves (1980) compared the effects of radiotherapy and surgery on 46 cervical cancer patients more than a year post-treatment. The surgically treated group had no significant change in sexual function after treatment but the irradiated patients experienced significant decreases in sexual enjoyment, ability to attain orgasm, libido, frequency of intercourse, opportunity, and sexual dreams. Myths about cancer and actual effects of pelvic irradiation were found to have disrupted the sexual-marital relationships of many of the women.

Andersen and Hacker (1983b) reviewed the literature on the impact of gynecological cancer on female sexuality. They looked at the relative impact of radiation therapy and radical hysterectomy. The consequences of radiation therapy may include dysfunction of the ovaries and stenosis (narrowing) and fibrosis of the vagina. Radical hysterectomy may involve removal of the ovaries and the upper third of the vagina. Premature menopause from either treatment can be a source of physical and mental distress. Some of the studies indicated that more fears and anxieties may be associated with radiation therapy and may decrease the frequency of sexual intercourse.

The best controlled study cited (Vincent, Vincent, Greiss & Linton, 1975) showed the least differences between the treatments. Vincent et al studied 50 women with stage I or II cervical cancer that was treatable by either surgery or radiation. They were randomly assigned to the two treatments. The women were interviewed after diagnosis, during treatment and six months post-treatment. The changes in sexual desire and sexual activity that both groups experienced were not significantly different. Twenty-four percent of those receiving radiation treatment and 20% of those receiving surgery experienced diminished desire, while 29% of those receiving radiation and 33% of those receiving surgery experienced decreased frequency of coitus. Andersen and Hacker suggested that a mediating factor for the women in the study may have been the opportunities to discuss their sexuality during and after treatment. These opportunities may have made it easier for most of the women to resume their normal sexual activities. Andersen and Hacker concluded the review with the suggestion that more long range studies need to be considered because the effects of radiation therapy may continue for two years after treatment and cannot be assessed until they have stabilized.

In summary no one treatment has been proved to be less disruptive to the women's lives. In fact the better the research design, the less significant the differences that emerged. However from the above research it can be concluded that in addition to the impact of the disease, treatment for gynecological cancer has a stressful impact on these patients.

These studies suggest that depression and poorer body image were common responses to gynecological cancer. Depression has been associated with severity of illness, levels of pain, and increased uncertainty about treatment and outcome. High levels of uncertainty were associated with poor communication both with medical staff and family members.

Adjustment to Gynecological Cancer over Time:

Burger (1981) reported on the first eight years after her diagnosis and radical hysterectomy and vaginectomy for cancer of the vagina. In the first six months she experienced depression over many losses including body parts, her previous level of health, her self-concept and her femininity. She discussed the effects of disease and treatment on her sexuality and her struggle to recover some level of sexual functioning in spite of urinary incontinence and extensive nerve damage. She stressed the importance of supportive counselling, of active participation in her medical recovery, of a supportive sexual relationship, and of sharing her experiences with others going through similar recovery processes. Burger added a personal perspective that underlined a number of issues and needs that were mentioned in larger studies.

Krouse (1985), in a longitudinal study of 21 women with breast and gynecological cancer, found that the gynecological oncology patients experienced worsening body images and greater depressive symptomology following treatment. At the end of 20 months follow-up, the women treated for breast cancer had stabilized emotionally "while women with gynecologic cancer continued to experience poorer body image and greater depression" (p. 46).

Krouse presented a model of the stages of adjustment from the time of diagnosis:

1. recognition/exploration
2. crisis/climax
3. adaptation/maladaptation
4. resolution/disorganization.

In the fourth stage, Krouse suggested that gynecological cancer patients either resolve earlier medical and psychological concerns or enter an extended time of behavioral and emotional disorganization. Krouse noted that while ideally these women regain much of their health and energy and resume their previous lives, most gynecological cancer patients who undergo extensive treatment

> continue to experience social withdrawal and dissatisfaction with sexual roles and relationships...Some women have persistent depression

> even though regaining physical strength and health (p.48).

Krouse observed some women who managed to resolve psychological issues even in the face of advancing illness and suggested that more studies need to be done to understand these individual differences.

In summary very little research has been done on the long term effects of gynecological cancer and treatment. Krouse's suggestion to focus on individual differences in facing advanced illness needs to be expanded to include studying individual differences in resolving the psychological issues surrounding recovery from cancer. The one long term study (20 months) suggested that affective distress tended to be long lasting among gynecological oncology patients.

Although these studies of interventions have had positive results in responding to the needs of women who have been recently diagnosed or treated, they do not address the long term needs of women who survive. Their focus is on psychosexual information and counselling and may not address other issues that women must confront if they are to resume their lives after cancer. Data collected within a longer time frame may alter some of the short term conclusions.

There has been little enough research of long term survivors of cervical cancer to warrant further exploration of these women's experience in order to generate hypotheses for future research.

Long Term Survivors of Cancer

Research about the quality of life of long term survivors did not develop until survival rates increased to the point that significant numbers of patients had lived long enough to consider their lives after cancer.

Kennedy, Tellegen, Kennedy and Havernick (1976) reported on one of the first studies to consider the psychosocial well-being of long term survivors. They studied 22 patients all of whom at one time had advanced cancer and had maintained a state of complete remission for 5 to 20 years since their last treatment: 13 males with testicular cancer, 1 male with lymphoma, 3 females with breast cancer, 2 females with endometrial cancer, and 3 females with Hodgkin's and lymphoma cancers. The data consisted of psychological assessment of the patients by their physicians, semantic differential tests, a differential personality questionnaire and personal interviews with the patients. They found that the cancer survivors reported generally positive attitudes toward life and the future. They had greater appreciation of time, life, people and interpersonal relationships than any of the comparison groups. The authors concluded that these patients became psychologically stronger for having faced the crisis of a life threatening disease.

Most of the patients in Kennedy's study indicated that they would have liked to know "early in the treatment program that other patients had succeeded in conquering the disease" (p. 2189). Kennedy et al noted some differences between male and female cancer survivors. The males reported higher stress reactions and the females put more value on friendship than the males.

Shanfield (1980) also conducted a study of twenty cancer patients who had survived from one to 33 years free of disease. The patients were diagnosed originally with a range of primaries including cancer of the breast (7), ovaries (1), and cervix (1) as well as various other cancers (11). The researcher found the following themes to be very frequent among the survivors: 1. "contagion" - passage of disease from one generation to another; 2. search for meaning of disease; 3. guilt for surviving; 4. response to healthcare system (anger for negligence, lack of support and threat to life); 5. major stress - actual or potential loss of loved one; 6. changes - refocussed priorities and greater appreciation for life; 7. confrontation with own mortality; 8. importance of support systems; 9. interview - eager to talk with and help other cancer patients; 10. vulnerability - feeling of continual damage and potential loss of life. Shanfield concluded that the study

> demonstrates the permanent impact and lasting importance of serious illness in adult life. Such

> events are shown in this study to have a certain predictability in adult development. The shift of priorities is seen as an important and regular aspect of having had life threatening illness, and suggests the creative use of the crisis of illness (p. 134).

Schmale et al (1983) studied 104 cancer patients who had survived one to eight years beyond their last treatment. The sample represented a range of cancer sites: 14 gynecologic, 12 breast, 10 Hodgkin's, 7 testicular, one each from 19 other sites, and 42 unidentified sites. The cancer patients showed marked differences only in the areas of lower sense of self control and of more general health worries than the control group. The researchers also found that survivors who were married and had not changed employment had significantly higher well-being scores. They conclude that "study of specific cancer patient groups might reveal more or less adjustment difficulty" (p. 168).

Danoff, Kramer, Irwin and Gottlieb (1983) developed an interview questionnaire to assess quality of life of long term survivors after definitive radiotherapy for various types of cancer. They interviewed 399 patients who were alive without evidence of disease, three or more years after initial treatment. They found that cancer patients as a group were more satisfied with religion, self and life than the national averages. The authors quoted Brickman as saying that victims of traumatic events had higher levels of perceived well-being after the event. In contrast a subgroup of their sample who had gynecologic malignancies (almost one quarter of the subjects in this study) and lymphomas (gender not specified) "were significantly less satisfied with their friends and social life and the amount of fun and physical exercise in their lives"(p.343). The authors concluded that the patients' perceptions of their quality of life are essential to assessing the impact of the disease and treatment on their lives.

Roud (1986) studied the experience of nine exceptional survivors of advanced malignant disease and found a high level of distress in the period just following treatment. Roud questions psychosocial data collected at the time of diagnosis and treatment (cf Cassileth, Lusk, Miller et al, 1985) as truly reflective of long term adaptation. He notes that the psychological states of these extraordinary survivors changed dramatically in the months following diagnosis.

> A variable that differentiates survivors from nonsurvivors may be their ability to psychologically change after disease onset...(p.121).

Other characteristics of the survivors studied by Roud were their positive expectations, assumption of responsibility for their health, trusting and meaningful relationship with medical staff, intense desire to live, sense that life had become very precious, and the individuality of their experience.

Longitudinal Studies:

Two studies have explored patient adaptation over time. Mages and Mendelsohn (1979) noted that the effects of cancer on patients' lives unfold over a long period of time and must be studied in a developmental perspective. Their study was based on the intensive analysis of a series of individual cases and the subsequent search for commonalities among them (p.256). They looked at permanent changes in time perspective, values, social roles, self-image, transitions and processes experienced by cancer patients. From these they identified a number of adaptive tasks that the patients must handle in coping with cancer. For example the third issue is "damage to one's body from the cancer and/or treatment." The adaptive task that follows is to "mourn the loss, replace or compensate for lost parts or functions where possible, and maximize other potentials so as to maintain a sense of self-esteem and intactness." The fourth issue is maintaining continuity. The adaptive task for this is to "understand and communicate one's changed attitudes, needs, and limitations in a way that permits formation of a new balance with the environment." The researchers also discuss basic modes of coping with cancer in relation to age and stage of life, sex, and personal history.

Fobair and Mages (1981) and Mages et al (1981) both report on a study of 35 patients who survived three to six years after their primary treatment and compared them with 31 patients six to twelve months after completing primary treatment. Each patient was interviewed for 4-6 hours in semi-structured interviews concerning changes they had experienced in self-image, mood, personal relationships, sexual life, assertiveness and work. The patients were grouped according to different patterns of response to cancer and recovery: doing well, bearing up, high distress and impairment, and unclassified. In the long term sample they found 14 patients who were doing well plus two who had re-organized previously chaotic lives through the cancer experience. They felt that in a larger sample the two who improved their life situation would be part of a more prominent group. Those who were doing well found life full and meaningful; they were concerned with work and family responsibilities; they maintained independence and enjoyed their families and friends. They tended to minimize or forget their initial distress and tried to put the cancer experience behind them. A few retained feelings of apprehension and felt diminished by the experience.

The researchers note, in comparing the recent patients to the longer term survivors, that those who showed chaotic maladaptation in the beginning did not improve over the years. Three factors that clearly related to the outcomes were:

1. Medical situation (severity of disease and treatment.

2. Previous psychological stability.
3. Network of social support.

In their discussion of the emotional effects of cancer and treatment, Holland and Rowland (1983) expand the list of factors that modulate the long term response of cancer:

1. Age at time of illness/disease
2. Type, site and course of disease
3. Treatment modalities
4. Implementation of rehabilitation
5. Social supports
6. Psychological support by the Home Care Team

The authors discuss a number of psychological sequelae in long term survivors such as fears around treatment and recurrence, adjustment to late effects, guilt about surviving when others died, grief over loss of secondary gains from the disease, vulnerability to depression, and the need to reassess values and the meaning of life. They also make recommendations for intervention with long term survivors including honest communication about diagnosis and long term side effects, planning for the end of active treatment and the decrease in contact with health care staff, monitoring patients for normal development and psychosocial needs, and provide psychological intervention where needed. They concluded that:

> More clinical studies of long survivors are needed to clarify the interaction of medical and psychological variables which contribute to quality of life of the cured cancer patient (p.31).

Stages of Survival:

Mullan (1984) also underlines the problems of cancer patients who survive long term. The major problems that he explores are fear of recurrence, learning to live with compromise, and economic and social shunning. He notes that all survivors go through extended periods in which they cannot be sure that they are disease free. They need to recognize that their fears are normal and to be expected as a part of the recovery process. Anger is also a normal response to loss and to living with compromise. Mullan also suggested the importance of mutual support among cancer patients, especially from experienced patients to novice patients.

In 1985, Mullan organized his description of the needs of cancer survivors into a progression of phases that he called "seasons" of survival. He defines survival as an "absolutely predictable but ill-defined condition that all cancer patients pass through as they struggle with their illness." He describes the seasons as "acute survival" where the patient faces diagnosis and copes with treatment; "extended survival" where the patient has completed treatment or gone into remission and must deal with physical limitations and the fear of recurrence; "permanent survival" where the patient faces the long term, secondary effects of treatment, problems with employment and insurance, and life-long concern with health.

> The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly, but also to map the middle ground of survivorship and minimize its medical and social hazards (p. 273).

From these studies it is apparent that cancer patients experience long term effects from their diagnosis and treatment. Recovery after treatment appears to be a major life transition involving identifiable stages. Survivors cope with the recovery process with varying degrees of effectiveness and attain varying levels of self reported quality of life. The review pointed a direction for further research in the areas of identifying issues in the recovery process and factors that might be important in adapting to the experience over the long term.

Chapter III: METHODOLOGY

The information in current research about recovered cervical cancer patients is limited and focuses on only certain aspects of their recovery, eg. sexual functioning. At the same time the literature has pointed out directions that need to be explored. The present study is designed to explore the experience and concerns of long terms survivors of cervical cancer.

Researchers use a qualitative design when the research question pertains to understanding or describing a particular phenomenon about which little is known or which would be difficult to assess by quantitative methods.

Qualitative Research Design

> "Before you impose your theories on the people you study, find out how those people define the world" (Spradley, 1979, p. 11).

The above quotation directly states the rationale for qualitative research of human behavior. In order to understand the experience of surviving cancer from the patient's point of view, it is necessary to have individual patients describe their world and to discover patterns in their perceptions and behaviors that will generate theories about that experience. The focus of qualitative research is on the meaning of the experience, on the context of the experience and on individual differences in responding to the experience.

Bogdan and Biklen (1982) stated that qualitative research is founded in part on the symbolic interaction tradition of social psychology. Jacob (1987) outlined the assumptions of symbolic interactionists and said that they

> assume that individuals' experiences are mediated by their own interpretation of experience. These interpretations are created by individuals through interaction with others and used by individuals to achieve specific goals. Symbolic interactionists are interested in understanding how these interpretations are developed and used by individuals in specific situations of interaction" (p. 27).

A major focus of this school of thought is on the development of self-concept in human beings through interaction with self and others. Chenitz and Swanson (1986) summarize the connection between self-concept and attaching meaning as follows.

> The human ability to hold a concept of self and for self-interaction is the basis for the formulation of meaning and experience in the world. ...Meaning is created by experience. Through interaction with the object and with self, the object is defined. Once defined, meaning can be attached to it. (p. 5)

This study focuses on individual interpretation of an experience and the meanings that evolved out of social interaction and personal reflection. However the symbolic interaction model does not present a specific method or set of procedures. Jacob (1987) included grounded theory as one approach used by symbolic interactionists for analyzing data. A grounded theory method was chosen for this study.

Grounded Theory Method

Overview of grounded theory:

Grounded theory is a method of systematically collecting and analyzing data for the purpose of generating theory about social and psychological phenomena. The goal of grounded theory is to generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved (Glaser, 1978, p. 93). Rennie, Phillips and Quartaro (1988) propose the following criteria for the theory:

> It should be believable in that it should seem to the reader to be a plausible explanation. It should be adequate in that it should present a comprehensive account that does not omit large or important portions of the data. It should be grounded in terms of the appropriate procedures and thereby inductively tied to the data. It should be applicable and should lead to hypotheses and additional investigation (p. 145)

In the grounded theory method, the researcher gathers data, builds a model, and develops a theory (Quartaro, 1986). Quartaro describes the process in five steps: 1) collection of data, 2) comparison of data, 3) integration of categories, 4) delimitation of the emerging theory, and 5) presentation of the theory.

Data Collection:

The initial sources of data are individuals who are representative of the problem under study. They are not selected at random but are chosen because of their knowledge and ability to communicate about the psychological processes being studied. In order to ensure richness of data informants should vary on other dimensions such as age, marital status, occupation. In the present study, data were collected from multiple interviews that were audio-tape-recorded and transcribed.

Analysis

In a grounded theory study, data collection, coding and analysis proceed concurrently. Interview data are transcribed and coded to identify process units in the data. These codes are descriptive labels that summarize a process unit or incident in the data and therefore are determined by the data. Coding facilitates the comparison of process units within an interview and between different interviews.

Stern (1986) outlined the steps of analysis that she used in her study of step-fathers:

> In four overlapping processes..., data were first coded for processes that occur during the course of observation or interview. Coded data were clustered into naturally related categories. Categories then were compared with one another and new data to discover links among categories. Categories so related were reduced and once again checked against incoming data to assess their pivotal relationship to emerging hypotheses. Concepts not supported in the data were dropped and new categories formed. Once formed, concepts were connected and reduced once more for increased abstraction and generalizability (p. 171).

The conceptual categories that Stern describes above are referred to as conceptual codes in Glaser (1978). He identified these codes as the essential link between the data and the emerging theory. He stated that theory is generated by "developing the hypothetical relationships between conceptual codes (categories and their properties)" (p. 55). Glaser described two levels of conceptual codes: "substantive codes" which conceptualize the "empirical substance" of the area of study and "theoretical codes" which conceptualize "how the substantive codes may relate to each other as hypotheses to be integrated into the theory" (p. 55).

Through the process of collapsing and linking the conceptual categories a single category or variable that is linked to all the others should emerge. This category is called the core variable and it has three essential characteristics: "it recurs frequently in the data, it links the various data together, and it explains much of the variation in the data" (Hutchinson, 1986, p.118).

> The generation of theory occurs around a core variable [which] accounts for most of the variation in a pattern of behavior....a basic social process (BSP)1 is one type of core category....a BSP processes a social or social psychological problem from the point of view of continuing social [or psychological] organization. Irrespective of whether it solves the problem to some degree, it processes it. A process is something which occurs over time and involves change over time. (Glaser, 1978, p. 93)

Through this process of comparative analysis a substantive theory begins to emerge. A substantive theory

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1 Glaser describes both basic social psychological processes (BSPP) and basic social structural processes (BSSP)and suggests that "the BSPP is more prevalent and relevant to the study of behavior." (Glaser, 1978, p. 102). For simplicity the phrase "basic psychosocial process" (BPP) will be used.

is one that is "well grounded in data that describes and in some cases predicts events or processes in a given social setting" (Stern, 1986, p. 171).

Reliability and Validity

Reliability in qualitative research is measured by the ability of subsequent researchers to follow the same procedures with a similar sample to get similar results. Although exact replication of research in human behavior is not possible, reliability is enhanced by clear and detailed descriptions of the individuals studied, the context, and the procedures followed in the study. Lincoln and Guba (1986) proposed that the report of a study should be auditable by another person who can follow the "decision trail" through clear information about the progression of events and about the logic of what was done and why. The present researcher had the good fortune of working with a study group of doctoral students who were pursuing grounded theory studies at the same time. These students acted as auditors for each other as their studies progressed. They met weekly to discuss difficulties they encountered and conceptual categories and hypotheses that emerged.

Chenitz and Swanson (1986) suggested that the question to ask is: if the resulting theory were applied to a similar situation, would it allow someone "to interpret, understand, and predict phenomena?" (p. 13). In this study the resulting theory was presented at two conferences and to other psychologists working at the cancer clinic, and it was found to be useful in interpreting the concerns of some other cancer patients.

In qualitative research, the main consideration regarding validity is how closely the data reflect the reality of the people studied ("meaningfulness") and not generalizability (Field and Morse, 1985, p. 122). The transcriptions were shared with the informants and they each had the opportunity to correct or expand their narratives. Second and third interviews with several informants gave them further opportunities to clarify their communication. One of the informants reviewed the descriptions of the conceptual categories and found them to reflect her own experience. The description of the process was presented to another female cancer patient (ovarian cancer) who also found the concepts relevant to her experience.

Delimitations and Limitations

Since the majority of the data consisted of self report material gathered at only one point in the patients' lives, the study is considered descriptive and retrospective. A retrospective study was appropriate because the focus of research was on a psychological process by which these women understand at the present time their experience of having had cancer.

Although this study did not begin with a theory about how these patients recover, it was delimited in areas of exploration on the basis of clinical experience of the researcher and on the basis of the review of literature. The study was open ended in regard to participant responses to experience of recovery. This study used interviews as a major source of data. Participant observation was not built into the study because the researcher had spent three years observing and interacting with cancer patients in a number of different settings in keeping with the general field work phase of ethnographic research and grounded theory studies.

In studying a specific population of cancer patients, the researcher recognizes that the results cannot be generalized to all cancer patients. The informants are all female adults living in or near one city. They were all treated at the same cancer clinic, and most of them saw the same radiation oncologist on their initial visits. In qualitative research the informants are not expected to represent all the variables in a population. The focus of this study was on individual experience and individual differences. However, the results suggest directions for future research regarding the psychosocial impact of surviving cancer.

Ethical Considerations

The researcher has protected the privacy of the participants in the study by reporting data without identifying information. Any material quoted from interviews has all identifying information removed (names, places) to protect confidentiality. The audio-tape-recordings and transcriptions were kept in locked storage in the researcher's office for the duration of the study. Afterward the audio-tapes were erased.

Participation was voluntary and the study was explained to those invited to participate. The participants were informed that they could choose to withdraw from the study at any time. The results were shared with any participants who expressed interested in knowing them.

The researcher is a chartered psychologist who is trained in interviewing people about psychosocial issues. She has been interviewing cancer patients and their families regularly for five years in her work as a psychologist with the cancer clinic where the study was conducted. She recognized the importance of keeping the roles of researcher and counsellor separate for the duration of the study. If the women participating had identified unresolved issues that they wished to address in counselling, they would have been referred to counselling services.

Implementation of the Study

Pilot Study

In the Fall of 1985, a pilot study was conducted with a small sample (12) of cervical cancer survivors from a cancer clinic in another part of the country. The purpose was to learn about their quality of life and their experience of recovery. Each woman was sent a questionnaire called the General Well-Being Schedule that included 68 scaled items plus five open ended questions pertaining to the research. The survey was followed up with a two hour in depth interview with one of the participants.

There were several difficulties encountered with the pilot study. First, the researcher had no control over the selection process beyond proposing the selection criteria. The medical records director of the clinic selected 18 files and presented them as the total population to fit those criteria. Second, securing the family physicians' permission to contact their patients proved to be a cumbersome process. Third, the General Well Being instrument was quite long and focussed on medical problems. Several women said that they did not want to take the time to respond to 73 items. In spite of the difficulties encountered in the pilot study, the project appeared worthwhile when the one woman who was interviewed commented that it was good to talk honestly about her experience and perhaps contribute to the recovery of others. Therefore the researcher decided to use a method of data collection that would allow more women to tell the story of their experiences in the ways that they want to tell them.

Setting:

The study was conducted through a busy regional comprehensive care cancer treatment and research centre. The professional staff are specialists in oncology and provide services to both in-patients and out-patients. The centre will be referred to as "the cancer clinic" in the remainder of this report. All the women who participated in the study had been treated at this clinic. Although the interviews were conducted in the homes of the women, the introductory letter indicated that the researcher was associated with the staff of the cancer clinic.

Sample Selection

As mentioned earlier, in qualitative research, the informants are chosen for their knowledge of the topic, their ability to communicate, and their willingness to share their knowledge and time with the researcher (Morse, 1986). In the researcher's view, all the women who had been treated for invasive cervical cancer and survived were knowledgeable about the experience. They were the experts on their own experience.

The large volume of data that can be obtained from individual informants necessarily limits the sample size.

In studies that use open-ended interviewing, the sample size would usually be less than ten. The researcher gathered data from additional informants until no new data emerged.

The sample was taken from the population of women in the region served by the cancer clinic who have survived invasive cervical cancer and have remained disease free for five to ten years after treatment. Cervical cancer survivors were chosen to be informants for several reasons. First as a group they share the characteristics of gender, age range, disease site and treatment modalities; so the influence of these factors should be constant for the whole population. Second, a great deal is known about the progression and prognosis of cervical cancer; and the demarcation of survival is fairly clear. Depending on the stage of disease at time of diagnosis, the critical period for succumbing to or surviving the disease varies from one to two and half years. By the fifth year after diagnosis, if there is no further evidence of disease, the patients can be fairly certain of long term survival. Finally, the cervical cancer patients have been well documented at the cancer clinic and the records are available for research investigation. At the cancer clinic former patients continue to be seen as part of their long term follow up program.

For the purposes of this study, survivors were those who have reached the point of at least five years but not more than ten years beyond diagnosis of cervical cancer and no longer are receiving treatment or showing any signs of disease. No evidence of disease means no local recurrence of cervical cancer, metastatic disease, second primary cancer sites, or other life threatening diseases.

The informants needed to be able and willing to communicate about their experience with the researcher. In order to participate in interviews, informants were selected who lived within 50 miles of Edmonton and who could be reached by telephone.

Beyond the basic criteria the researcher selected informants who represent variability in age, marital status, employment status and other factors that could limit generalizability of the theoretical results.

In July 1988, the researcher was given access to a database of 551 names that included all of those women who had been treated for invasive cervical cancer at the cancer clinic over a 17 year period and who were known to be alive and free of cancer at their last contact with the clinic. By eliminating all the women who were treated more than ten years before the study commenced, the list was reduced to 136. By applying the further criteria - diagnostic stage IA2 or greater, age less than 70, local area address, and last contact in within two years - the list was reduced to

21 women. A chart review indicated that two of these women did not speak English, two had moved away, and two had recurrent disease. When the resulting list was reviewed by the attending physicians at the cancer clinic, two more names were eliminated because they already had participated in a longitudinal psychosocial study. Therefore 13 constituted the potential sample.

Procedures

Letters were sent out to the first six women on the list inviting them to participate and alerting them about telephone contact the following week. See Appendix A. During the telephone contact, the study and their potential participation were described again. The niece of one woman explained that her aunt was elderly and did not speak English well so preferred not to be interviewed. The others agreed to participate, so appointments were arranged. Over the next few months seven more letters were sent out. Two more women chose not to participate: one said she did not want to think about the past and one felt it was an invasion of privacy. However, five more interviews were set up. In total ten women were interviewed. The number of informants exceeded the requirements of theoretical sampling but ensured that the data were rich and varied.

The researcher met with each woman in her home at a time that was convenient to her. Any further questions were answered and each informant was asked to sign the consent form and to fill out a brief data form. See Appendix B and C.

Interviews:

Consistent with data collection of qualitative studies, the informants were invited to tell the stories of their recoveries in their own way in order to discover the events, ideas, feelings that they considered important to their experience. The interviews all began with the statement that

> "We know a lot about women's experiences with diagnosis and treatment and the time immediately following treatment, but we do not know about the experience of these women five to ten years after treatment. Please tell me about your experience."

Then each informant chose the focus of her story. Her story then guided the questioning to greater elaboration of events described and exploration of areas not mentioned in the story but relevant to the research questions. Then the researcher asked more specific questions to assist in the understanding of the following areas:

1. The informants were asked if there was anything (event, person, belief etc.) in their experience that prepared them to cope with cancer.

2. They were asked if they had developed any theories about they came to have cancer and any theories about how they came to survive. They were asked if any of their ideas changed over time.

3. The informants were asked about whether they felt "recovered" or not and to what degree. Was there a time when they felt that they had recovered?

4. What do they remember as important experiences during the process of recovery (or time since treatment)? Were there any milestones in the recovery process? What issues did they confront in the process of recovering and how did they cope with these?

5. The informants were told that much research is being done on the quality of life and that the researchers have concluded that the definition is a personal matter. They were asked what their personal criteria (what they needed to have, do or be) for good quality of life: what makes life worth living for each of them.

6. They were asked about how their level of quality of life may have changed since their experiences with cancer? Had their priorities for quality of life changed since their experiences with cancer?

7. The informants were asked what factors (experiences, coping strategies, psychosocial support) contributed to their current level of quality of life.

8. Finally, the informants were asked if they have suggestions for other women who will go through the experience of surviving cervical cancer.

The interviews were about 90 minutes long. Most of the women felt they had said all they wanted to say in one interview. Each informant was sent a transcript of her initial interview so that she could add comments. Four women returned the transcripts with additional comments. One of those four was a woman who did not want to be tape recorded but did agree that the researcher could write a summary of the interview. The researcher sent her the summary and a page of additional questions that were not covered in the initial interview. She returned the summary with corrections and answered the questions.

The researcher conducted follow up interviews with two of the women to clarify and expand issues they had raised. A third interview was conducted with one of these two women about nine months after the first interview. The focus of the third interview was on reviewing the description of the conceptual categories. There was one more interview with a survivor of ovarian cancer who also assessed the description of the process as reflecting her own experience.

Total interviewing time per woman ranged from one to four hours. The interviews were audio-taped, transcribed and analyzed for common themes and unique approaches to recovering from cancer.

The researcher kept notes on her observations and her own responses to the interviewing process. She also kept notes on the developing categories and hypotheses during the research process. These activities are called "memoing" by Glaser and Strauss (1967) and others who use the grounded theory approach. Memoing is a major strategy in theory development.

In order to monitor the process of interviewing and prevent distortion of the data by guiding the initial narratives, the researcher checked the first few transcripts with her thesis advisor and modified her interviewing style according to the feedback she received.

The literature on qualitative research frequently focuses on the researcher as the main instrument of the research. The researcher endeavors to reduce observer effect, knowing that it cannot be eliminated. In this study the researcher is familiar with the treatment centre and with many of the physicians and patients. However, the focus of the researcher's clinical work has been on patients who are beginning, going through, or just completing treatment. The informants in this study were well passed active treatment, so the researcher could approach them with few expectations about their needs and perceptions.

However, the researcher recognized that her exposure to the diagnosis and treatment process and her training as a professional had the potential to sensitize her to specific issues. To the best of the researcher's ability throughout the study, she attempted to remain aware of such pre-study assumptions that may have been a result of her background which included: an existential perspective, a family systems perspective and formal clinical experience in health psychology.

From an existential perspective, the researcher assumed that an encounter with a potentially life threatening disease would cause most people to search for meaning in the experience and possibly modify the meaning of their lives. The researcher expected that the individual's attitude toward the experience of having cancer would have a major effect on how she recovered from that experience.

From a family systems perspective, the researcher expected that relationships with family members might form a major resource for coping with illness and recovery. However the researcher decided to interview only the patients in order to let them define what were the important sources of support in the experience.

Clinical training in health psyhcology does emphasize formal psychological interventions in helping patients deal with psychosocial problems. Nonetheless, the researcher's extensive clinical experience had made her aware many forms of informal support and resources for coping that patients commonly use. The researcher attempted to remain open to the potential that informants might differ in minor or substantial ways from the type of person who seeks professional help.

Process of Analysis:

The first three interviews were analyzed to identify units of process (also called incidents or meaning units). These units were compared from one interview to another and with units identified within each interview. The units were grouped into similar types of incidents or behaviors that were common across the interviews. These units or incidents became the descriptive or "substantive" codes (Glaser, 1978, p. 56) that were then applied to subsequent interviews to identify similar incidents. Each subsequent interview was analyzed for new incidents, and the substantive codes were modified to more accurately reflect the women's experiences.

The researcher looked for negative cases, i.e. experiences that would not fit the "typical" pattern. For example the experiences of the women who recovered physically relatively quickly were compared to the experiences of the women who had chronic symptoms. Other examples of comparisons included older versus younger women and married versus unmarried women.

At this point in the analysis process, in order to balance the fragmentation of experience that occurs in examining incidents, the researcher wrote a brief summary of each woman's experience. These summaries are found in Appendix D. The names have been changed to protect the individual identities.

After all the interviews were analyzed and the substantive codes were refined, the substantive codes were linked together in hypothetical relationships. These conceptual groups are referred to as "theoretical codes" in Glaser (1978). He explained that :

> theoretical codes conceptualize how substantive codes may relate to each other as hypotheses to be integrated into a theory (p. 72).

Glaser presented a number of groupings of such codes that he called "coding families." He noted these families

> are not mutually exclusive, they overlap considerably. Also one family can spawn another. Their conceptual level in relation to each other is also arbitrary by their use. Some are different ways of saying the same thing. (p. 73).

To organize the data from this study, the following theoretical codes were chosen (with coding family in parentheses): self ("identity-self"), phases ("process"), contexts, conditions, impact ("six C's"), and strategies (strategy). These will be defined at the beginning of Chapter V: Theory Overview.

In the early stages of analysis it appeared that "making sense" might be the core variable because it was a category that appeared frequently in the data and initially organized the categories in a meaningful way. However with further analysis, "making sense" fitted into the theoretical code of "strategies" as an important linking category. Finally a unifying process emerged to organize

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2 Glaser's "Six C's" are causes, contexts, contingencies, consequences, covariances, and conditions.

all the categories: "maintaining the self." The basic psychosocial process "maintaining the self" will be introduced in Chapter IV, elaborated in Chapter V and discussed in relation to relevant literature in Chapter VI.

Chapter IV: THEORY OVERVIEW

Basic Psychosocial Process: Maintaining the Self

The purpose of this study was to generate substantive theory about the processes which account for the present experience of ten women who survived invasive cervical cancer as described by these women seven to ten years after the completion of treatment.

The purpose of this overview is to introduce the basic psychosocial process of this study which emerged as "maintaining the self". Maintaining the self is a psychological process because it focuses on self-concept which is a psychological construct. It also is a social process because the self-concept, as used in this theory, is developed through social interaction and communication as well as individual interpretation and integration.

The analysis of the data suggested that the experience of being diagnosed with and treated for cancer had an impact on the lives of these women that unfolded over time, even long after treatment was completed. The focus of the impact was on how the women saw themselves as changed by the experiences they described. At the same time the women each expressed a sense of continuity with who they were before the experience. Therefore the basic psychosocial process is called "maintaining the self."

In order to understand the following chapter where the whole process is described, several terms need to be defined and explained. The first term is the "self" or "self-concept" and it will be explored in the next section. After that the other terms chosen as theoretical codes will be presented.

The Focus on Self

A life threatening illness threatens the way a person organizes her perceptions of the world and herself. Moos (1982) described the impact of a health crisis as follows:

> A situation so novel or so major that the usual, habitual responses are inadequate to deal with it constitutes a crisis and leads to a state of disorganization often accompanied by heightened fear, guilt, or other unpleasant feelings which contribute further to disorganization. (p. 130)

The organization that is threatened is what writers such as Epstein (1973) call the self-concept or self-theory. Seymour Epstein explored historical perspectives on self-concept and concluded that what is being considered is a self-theory.

> It is a theory that the individual has unwittingly constructed about himself as an experiencing, functioning individual, and it is part of a broader theory which he holds with respect to his entire range of significant experience (p. 407).

Epstein proposed that a self-theory has at least three functions: 1)"to optimize the pleasure/pain balance of the individual over the course of a lifetime", 2)"to facilitate the maintenance of self-esteem", and 3)"to organize the data of experience in a manner than can be coped with effectively" (p. 407). He said that it was "essential for the functioning of the individual that the organization of the self-concept be maintained" (p. 407). The self theory is both the framework the individual brings to a situation and the activity of organizing perceptions of that situation. The idea of self as a framework will be included under the heading "contexts." Epstein compared the individual attempting to solve the problems of daily life with a scientist.

> Both continuously make and test hypotheses and revise their concepts accordingly. Both organize their observations into schemata which then are organized into a network of broader schemata called theories... Without such a system, the individual would be overwhelmed by innumerable isolated details that would have to be recalled to guide behavior (p. 408).

For the purpose of this theory, the self is a psychological construct or set of schemata with which the person organizes data of experience and beliefs about who she is in relationship to others.

The problem for people faced with a major health crisis is to maintain stability within their self-concept in order to cope with the needs of the situation. Moos (1982) stated that "health crises usually cannot be anticipated, their meaning for the individual is ambiguous, clear information is lacking, and it is often necessary to make definitive decisions quickly" (p. 130). The psychological problem faced by cancer patients is dealing with uncertainty. Patients ask themselves questions such as "Am I going to live or die?" "Why did I get cancer?" "What are the long-term effects of treatment?" "Have they cured me?" "Will the cancer recur?" "Will I be at risk for another kind of cancer?"

The Theoretical Codes

As described at the end of Chapter III, the following theoretical codes emerged from an analysis of the substantive codes and form the elements of the process of maintaining the self: self (already described), phases, contexts, conditions, impact, and strategies. The emergence of these theoretical codes from the data during the process of analysis is described in the previous chapter.

Phases:

According to Glaser, a process must have two or more sequential parts; and "maintaining the self" is a process that takes place over time in two sequential phases. The sequential parts of this process overlap more than might be expected of distinct stages, so the term "phase" has been employed to refer to each of two sequential parts. These phases are defined by external events and the ways these events interact with each woman's sense of herself.

The first phase focuses on experiences around the diagnosis and treatment of cancer. Phase I is called "defining and defending the self" because it concerns each woman's encountering and efforts to deal with events that threaten her life and her concept of herself as a well person. This phase is divided into two parts: the first part concerns diagnosis and the second part concerns treatment at the cancer clinic. However, it is well to keep in mind that in reality diagnosis and treatment overlap. That is, some of the women had surgery before being referred to the cancer clinic and all the women received further diagnostic assessment at the clinic.

The end of primary treatment at the cancer clinic marks the end of phase I and the beginning of phase II: "adapting and reclaiming the self." This phase involves long term adaptation and re-establishing a sense of self as normal and healthy. Phase II also is subdivided into two parts with different concerns. The first part, called "relearning your life" concerns adapting to the consequences of treatment and re-establishing some sense of normal living. The focus of this part is on the women's immediate needs after treatment. The second part, called "looking to the future" concerns issues that go beyond immediate needs, such as living with changed priorities and goals and facing normal aging. There was no clear evidence in the data to suggest that the women put off thinking about the future until their adaptive tasks were completed. It may be that these two parts of phase II happen simultaneously. However because the time orientation of part A is on the present and part B is on the future, the two parts will be considered sequentially. The sequential phases that emerged are partially consistent with Mullan (1985) and will be discussed in Chapter VI.

The events and interactions relevant to the first part of phase I, concerning diagnosis, will be used for examples to illustrate each theoretical category.

Contexts:

The term context originally was used to describe the parts of written text "which immediately precede or follow any particular passage or text and determine its meaning" (Onions, 1980, p. 412). In the field of human communication context refers to all the factors in the environment and in the situation surrounding the communication that define or add to the meaning of the communication. These might include social roles and status, rules and rituals, beliefs and values that form parts of the frame of reference of each participant in the communication.

Behavior happens in context, and it is the context or contexts that give meaning to the behavior. People respond to behavior and events according to the meaning and evaluation that they attach to them.

> A phenomenon remains unexplainable as long as the range of observations is not wide enough to include the context in which the phenomenon occurs. (Watzlawick, Beavin & Jackson, 1967, p. 20)

In describing the process of maintaining the self, three "contexts" will be considered: the self (already described), the social system and the medical system. The self referred to here is the self-concept or self-theory that the individual brings to the experience. Since the self-concept is a way of organizing what is perceived according to cognitive structures developed over time, it is a context that the women bring to their experiences. The context of self includes experiences, beliefs and values from the past. The self system could also be called the intrapsychic dimension for the experience. The social and medical systems are elements of the interpersonal dimension of the experience. These three contexts interact over time and are influenced by the experience.

The social system includes family and friends, work place, community, religious and cultural beliefs and customs, and mass media. Any of these elements might have greater or lesser impact according to the relevance to the individual woman concerned. The women's experiences of relationships with family and friends varied in the degree of involvement and degree of influence of those relationships. Although all but two women were born and raised in Alberta, they came from a variety of cultural frameworks, with differing values, beliefs, roles, and customs.

Although the medical system is part of the general social system, it plays a separate role in the experience with illness. The women had to deal with their illness in the context of the medical system and deal with beliefs and values that were or were not congruent with the beliefs and values held by themselves and by their social environment.

For example at the time of diagnosis, a woman would view the information that she has cancer in the context of all her past experiences as well as her beliefs and values regarding her self and illness. At the same time she receives the information in the context of the medical system, perhaps represented by her family physician or a gynecologist who also brings a set of expectations, beliefs and values to the experience as well. The interaction of these two contexts will influence the impact of the experience for the woman.

How the various systems - the self, the social, the medical systems - interact, depends on the congruity between belief systems and the amount of influence each system has during any particular event. For example a native woman, who came from a social system where people did not trust the non-native medical system, had had good experiences with hospital care for the births of her children. She was ready to trust in the efficacy of hospital medical care because it was congruent with her personal experience even though it was not congruent with some aspects of her social system.

Condition:

"Conditions" describes the circumstances over which the women had no control but which precipitated the need to respond. For example, hearing that one has cancer is an event and a condition to which the women responded by feeling vulnerable and seeking support.

The conditions of the first phase are "finding out you have cancer" and "going through treatment." These conditions defined the situation with which the women had to cope.

The consequences of "going through treatment" become the conditions of phase II part A: "relearning your life". The condition of part B, "looking to the future", is "re-assessment of quality of life".

Impact on the Self:

Although Glaser suggested the theoretical category of "consequences", the vernacular "impact" was chosen as similar but implying influence or impression left by something rather than being the end result of a specific cause.

In hearing the diagnosis of cancer, examples of the impact on the self were the feelings of vulnerability and uncertainty about the future that the women expressed. The two youngest women noted that they could no longer see themselves as invulnerable and secure. While not disintegrating their concepts of self, it did require them to broaden the views of themselves to include illness and potential dissolution.

Strategies:

The last theoretical category is "strategies" which includes all the cognitions and behaviors that the women employed to deal with their circumstances and the impact on themselves. For example, after hearing the diagnosis, a coping strategy would be talking to someone who might provide support and validation of the self. Specifically, one woman called her husband from the doctor's office, and then she and her husband sat and cried together. Telling her husband gave her the opportunity to receive emotional support.

A special kind of coping strategy that appears often in the description of process and that appears to be essential to the maintenance of the self-theory was "making sense". "Making sense" is associated with the function of "organizing the data of experience in a manner that can be coped with effectively." It would seem that making sense of a threatening event and maintaining a self-theory are inextricably interwoven.

"Making sense" is not global but focussed on the present and possible options for the next step: dealing with one thing at a time, creating a working model or map of the immediate situation without considering all the ramifications. A map may be changed as new information is presented but its general outlines tend to remain. Making sense attempts to answer immediate questions about what to do next and how to get there. "Making sense" is a way of containing uncertainty before it becomes overwhelming.

In summary, this overview has included an introduction to the basic psychosocial process of "maintaining the self", the reasons for the focus on the self, and a presentation of theoretical terms to be employed in the next chapter. The next chapter will present the phases in sequence and include quotations from the interviews to support each theoretical category.

Diagram: BASIC PSYCHOSOCIAL PROCESS: MAINTAINING THE SELF

PHASE I: REDEFINING AND DEFENDING THE SELF

Contexts: The Self System, Social System, Medical System

Condition	Impact on the Self	Strategies
Part A: Diagnosis		
Finding out that you have cancer	Vulnerability Uncertainty	Telling others Seeking support
Part B: Treatment		
Going through Treatment	Physical threats Social threats Psychological threats	Relating to doctor Developing a map Learning hospital culture Other patients Social comparisons Using Humor Making sense

PHASE II: ADAPTING AND RECLAIMING THE SELF:

Contexts: The Self System, Social System, Medical System

Condition	Impact on the Self	Strategies
Part A: Relearning your life		
Consequences of cancer and treatment		Back to normal Living with limits Pushing the limits Caring for self
	Reclaiming the self	Making sense
Part B: Looking to the future		
Re-assessing quality of life		Living with changes Fears of recurrence Facing normal aging
	Becoming a model	Telling the story

Chapter V: DESCRIPTION OF THE PROCESS OF MAINTAINING THE SELF

Phase I: Redefining and defending the self:

The first phase in the process of "maintaining the self" is becoming a cancer patient. The diagnosis of cancer had a significant impact on each woman who told her story. Not only was her life threatened but her perception of herself as a healthy person was challenged. Therefore this phase is called "redefining and defending the self". Understanding that the "self" is a dynamic theory that has both stable and developing dimensions, activity of "redefining the self" includes expanding the self-concept to include "cancer patient". "Defending the self" focusses on maintaining the stable dimension of the self-concept in spite of the new information.

This phase can be more easily described when it is broken into two parts, the first focussed on diagnosis and the second focussed on treatment. However the division is somewhat arbitrary since diagnosis and treatment tended to overlap considerably.

During this phase each woman's personal system of experiences, values and beliefs interacted with the social system and the medical system.

Contexts:

The Self System:

Each woman brought her individual personality and experience to the events surrounding her diagnosis with cancer. Each woman had a repertoire of coping strategies that made up her coping style or how she perceived her capacity for coping.

> I'm not the kind of person who makes crises out of things. Like you just say that this is the way it is, deal with it, and get on with life.

Each woman had beliefs and values about herself, life and cancer in particular.

> I guess I'm a person that doesn't take change easy.

> I had a deep seated sense that nothing really bad could happen to me.

> I'm from a different generation. I know that years ago cancer was a dirty word like AIDS is today.

Life experience also played a role in how the women understood their experience of cancer. Individual experience ranged from no experience of hardships, losses or illness to many such experiences.

> I think this is the only traumatic event I've ever experienced in my life.(B)

> Because in my family my mother died when I was five... and then my father died early, and I lost two sisters....Anyway so you're aware it can happen, just it now can happen.

The women's knowledge of cancer also varied from very little to specific medical knowledge or to experiences with cancer in their own families.

> I've never been around people with cancer.
>
> Well my dad had leukemia, and he was 46 when he passed away....I was about 16....They didn't have the knowledge like they have now, all these treatments.(K)

Medical System:

The context of the medical system had the greatest influence on the meaning of the experience for most of the women at this point. It was in the medical context that they were presented with the information that they had cancer and were about to become cancer patients. The authority of the physician in this context meant that the information could not be discounted. The influence of this context will be seen through out the first phase.

Social System:

Although the social system had somewhat less power than the medical system to define the meaning of "cancer patient" for the women it was still important in defining who they were in relationship to the significant people in their lives. It was in that context that the women decided whom to tell about their new diagnosis of cancer.

Daily involvement in the work setting took precedence for some over long time friends or family who may have been geographically distant. The work place also assumed greater importance for those who were not married and self supporting. An example of a multidimensional support network that includes close friends, people at work, and distant acquaintances is described in the following statement:

> My closest, oldest friends are all in [another city]. So that group of people isn't involved with me on a daily basis. But people, my friends at work are very understanding...And people, not even who work with me but distant people who just see me occasionally, they'll say, "Oh yeah, I think about you and decide I better go to work: if you can do it, I can do it."

Part A: Diagnosis

Although the first part of "Phase I" begins with pre-existing conditions that led to the first signs and symptoms of cancer, the moment of receiving the diagnosis was clearly remembered by all the women.

Condition:

Finding out that you have cancer

Most of the women began their narratives by relating how they were told that they had cancer and the impact they experienced.

Finding out that you have cancer precipitates questions and the need to make sense of what is happening. How this comes about depends on a number of conditions such as having symptoms, having a doctor and having tests. There is an interaction between the contexts of the personal and the health care systems. Some women experienced delays that they attributed to assumptions that the doctor should have told them if an "abnormal papsmear" needed to be followed up. In some cases the women changed doctors in order to have the necessary assessment and referral to the clinic.

> I had an appointment to see [the doctor] a week later, and his nurse called me like two days later and said he wants to see me tomorrow. So I said I don't think I like the sound of this but I think I will go to the appointment.

Hearing the word cancer triggered negative associations: belief that cancer meant death, memories of people who had cancer, fears of illness. Several women remembered the exact circumstances when they heard the diagnosis.

> When they told me that, I said that must mean I'm going to die because everybody who had cancer that I ever heard of was going to die....I found out on a Thursday at 3 o'clock. I mean I know the details of that real clear even though that was a long time ago;...it was traumatic and you remember traumatic things.

> I guess to be told you have cancer is a frightening thing. But in my case, I just felt like, alright, let's take care of it. And then it's done. And then you go on your way.

Impact on the Self:

1. Feeling vulnerable: First you cry.

The women reacted with shock, fear and a sense of loss, and most often they cried. Their reactions were both emotional and cognitive.

> Like it was the most traumatic day of my entire life.

> You think, oh you're going to die...that's the first thing that hits you. You go through that process of grieving. and then you accept it.

To a greater or lesser degree each woman felt her knowledge of herself was challenged or even threatened by the diagnosis of cancer.

> [In the beginning] you're very threatened: the 'you' is threatened, the essence of you. Everything that you know about you is changing. It's being swept out from under you, and you don't know what is going to happen.

2. Experiencing the uncertainty:

Most of them found themselves asking why they had cancer and why at that time (asking questions). They drew on memories and sought out information so that they could make sense of the situation (seeking information). Some used the strategy of reading everything they could get their hands on about cancer. Some turned to religious beliefs and began to pray.

At this point most felt a disequilibrium and a need to make sense of their situation. However they realized at some level that it "made sense " to accept the diagnosis and to accept treatment. Some said they had no choice but one contrasted her own experience with another woman who refused treatment for another kind of cancer and died of the cancer.

> I thought, why have I got it. What have I done wrong to have cancer you know.
>
> So I just read every, a lot of books on cancer. And some were good and some were, the technical things were very boring and were not helpful to me.

Strategies:

Telling others and seeking support

This behavior was a consequence of feeling the impact of diagnosis and involved interaction between each woman and her social environment. Telling others had several functions: it validated the reality of her situation; it provided others with the opportunity to offer support; and it fulfilled obligations to some work situations.

1. Talking to family and friends: After diagnosis each woman had to decide whom she would tell or not tell among her family and friends. Her decision was most often influenced by her marital status - married women told their spouses first and single women told their parents or children first - and by the availability of a close circle of friends or church group who could provide support.

> I phoned [her husband] at work and I told him...he left work and came straight over...I think we just sat out in the car and bawled our eyes out.
>
> When you're single...there tends not to be anyone you can talk to in a really specific way...mostly when they're married women, their husbands are very involved in the decisions.
>
> I didn't want to tell the family. I didn't want to tell anybody when I found out I had it....to this day I've never told my mother....I always thought why bother her...older people they worry more.

2. Talking to people at work: Work mates and supervisors provided daily support for two women who were not married. However the third perceived a potential

threat from workmates in the sense that they might label her or give her negative feed back.

> I didn't want to discuss it with anybody because I felt I didn't need anything negative....people like your co-workers, as long as they didn't know anything about my problems, then I wouldn't have to worry about what they were saying about me.

The women who did tell family and co-workers then had to cope with the reactions of those significant others to the illness. Some of the reactions included upset, silence and over- concern, as well as positive support such as help with daily tasks, prayer, attending clinic with the woman. When support was offered the women had to choose whether to utilize it or not.

> She put on a good front...and you could see where she had been crying all day long...but she gradually kind of got over it.

> They'd come and bring cards and gifts... [make] phone calls when you're home.. and of course they always ask if you needed help at home, if you need help with cleaning and cooking. We didn't really need help because the boys were old enough.

Reactions from her children pushed one woman to take a position in regard to surviving. Her child's question became a challenge to her:

> "Mummy are you going to die?" and stuff like that. I said "no, I'm not going to die" - not knowing myself whether I was or not...And maybe it was even then that I made up my mind that I wasn't going to [die]. I don't know, it could have been.

Part B: Treatment at the Cancer Clinic

The second part of the first stage begins with a referral to the cancer clinic. This part involved further assessment but in the narratives of the women both were mixed together.

Condition:

Going through Treatment:

This condition consisted of meeting the clinic physicians and becoming a cancer patient in the context of the medical system.

In most cases these women met with the radiation oncologist because they were treated with radiation externally and internally. Some of them had surgery, a hysterectomy, either before or after the radiation treatment.

Impact on the Self:

1. Physical threats to self:

Reported discomfort during treatment and soon afterward included vomiting, burning sensation in the irradiated area, and fatigue. All of the women were able to cope with these symptoms on a short term basis.

> When I know there's something wrong, it doesn't bother me. They put tne dye into my feet. That was the only thing I didn't like.

> The way they've got it timed was exactly right for me because had I had another day I would not have gone. It just took everything out of me. I was very very sick for that last one.

The long term effects of treatment included menopause, sexual dysfunction, diarrhea, cystitis. Menopause was universal but varied in impact according to age, meaning of childbearing, and severity of symptoms. Again all had changes in the vaginal canal: impact on sexual functioning varied with severity of changes, availability of a sexual partner, and the nature of the relationship.

> For awhile I felt very irritated every time my husband tried to touch me...it would be all I could do to hold back from just telling him to get away from me. But I've kind of learned to cope with it.

2. Social threats to self:

Disruptions: At the very least, all the women lost several months of time from work and other activities. One woman quit her job for a year but returned to the same place of work. Several described limits in their ability to work during the months after treatment. Those with complications had the most constraints on social activities.

> I have to be very careful even just going to the store you know. I have to know where I'm going and first thing when I get there I have to know where the washrooms are, just in case. We don't go to a lot of parties [unless] it's someone I know very well, like my Mom.

Changes in relationships include improved spousal relationships, closeness with other family members, friends who became closer or more distant, people in general who were helpful or not helpful.

> We just got closer. Maybe he grew up more, but it just seemed to happen at the time that I got cancer. ...He just stayed home with me... We expressed our feelings to each other which we never did so much before...Something clicked in him like, Gee maybe I'm going to lose her.'

> Yeah well for the job, I had a guy that used my cancer, trying to beat me out of my job type deal. What he did was he went to my bosses and said, "I

> don't think she should have the job because she had cancer."

3. Psychological threats to self:

A grieving process was identified by several of the women. Grieving was focussed on changed or lost body parts, on loss of time or activities, on loss of ability to have children, on loss of freedom or loss of a sense of invulnerability.

> You go through that process of grieving....You know, you're only that young and you're going to die and you're going to leave your family behind.

> You've had a loss, so you have to cope with that ...a loss of time, six months or a year...when you couldn't be the way you used to be. And then in my case I had a loss of my body part which physically is very demanding but also emotionally.

These women found that they had to make sense out of their losses in order to resolve their grief. Losses that enabled them to survive could be accepted.

Strategies:

Relating with the cancer doctor:

Most of the women described their experiences of meeting the radiation oncologist as a turning point in how they perceived the crisis of having cancer.

Several of the women mentioned the importance of trust or confidence in their physicians when they felt so vulnerable in themselves. Vulnerability was felt in regard to loss of control over their bodies.

> When a large part of your life is already controlled by others, you know, there's your whole body is in the control of all these doctors.

When the person to person relationship was established between doctor and patient, then the trust developed.

> And she sat me down and talked to me like a real intelligent human being, a person who is not the disease but the person who happens to have the disease....I trusted her completely.

Rapport building factors included how the physician presented information as well as the physician's professional manner, positive attitude and gender.

> I think it helped that we are both professionals.

> I remember the nurse...She was very um, well sympathetic anyway, because I think she felt his [the physician's] lack of compassion and understanding.

> ...for women's problems especially, they can explain it much better somehow because they're a woman themselves, and she was very good.

None of the women expressed a wish to make medical decisions but all expressed a need to know what was going to happen. Some of the women asked for details about alternatives, risks and side effects. For one of the women trust was undermined by disagreement between the surgeon and the radiation oncologist about adjuvant treatment.

> My surgeon felt the radiation wasn't necessary... you know its a gambling game: if you choose not to do it then you might be choosing the wrong thing...but [at the cancer clinic] there was no discussion: you have to have it...I wasn't in peak condition... I was basically on my own...I would not allow anyone else to make that decision for me.

Developing a map:

As their situation was uncertain, the women needed enough information about where they were, how they got there and where they were going in order to regain some sense of control. In a sense they gained a functional map of their situation that reassured them that they were not going to die and that the disease and treatment were knowable. For a couple of the women the map was a result of their religious beliefs: if they prayed then God would heal and guide them.

> It takes a long time to even recognize what you have to deal with...When the doctor tells you you've got cancer that's the first step. You have no idea how surgery is going to make you feel. So then you have surgery. So that's more information.

> I thought...God can hear my prayer and heal me and I won't have to die. And if it's his will, I will die. So I accepted it that way....the nurse told me that she didn't expect me to come out that well. Because, well, my friends and family were all praying for me.

Learning hospital culture:

The hospital environment is a subculture that involves a set of roles, rules, practices and beliefs that are followed in that setting and that may or may not be congruent with the roles, rules, practices and beliefs of the general society. Examples of how the women perceived the cancer hospital environment is described in the following statements:

> And sitting in the [clinic] for four hours, waiting wasn't pleasant either.... Then five weeks of radiation treatment were very hard... And you have weekly recalls there to talk to a doctor. You go in ever morning. And I must commend the nurses...they were really helpful in getting me in right at 8:00. And I'd rush out to work.

> And I mean I've been in a few hospitals over my life that I've got all praise for the [cancer hospital]. I think it was really an excellent hospital and I don't know, to me, but it feels like they're hand picked

> staff. I'm sure they are, from the girl at the desk [to the staff] on the wards. They didn't bring their troubles to work at any rate, you know, which they could have done... They were all nice staff. I didn't find one that was unpleasant.

What stood out in terms of the informants' perceptions was the support aspect of hospital culture. Generally the women mentioned the nursing staff or how the staff were all good from the receptionist to the physician. Some gave details of tests and treatments. Hospital culture (with its rules, roles and rituals) is perhaps more implied than stated.

Connecting with other patients:

For several women talking with other patients was a way to 'normalize' the hospital experience.

> When you go to the clinic, you just speak to one another when you're there as a patient. And even that is good, you know, when patients talk about their ailments and stuff. But it's good therapy.

Social comparisons:

Most of the women minimized the psychological impact by comparing themselves to worse cases: those who had cancers with worse prognoses or worse side effects from treatment or those who had other handicaps or who had died. The women found talking about people that they considered worse off than themselves helped them to stop feeling sorry for themselves.

> You meet more people; and of course when you're at the cancer hospital, you realize, you think, well why am I here? So there's people a lot worse than you in there at any rate, you know.

> I'm not deaf, dumb, blind. I'm not crippled in a wheel chair. I refuse to feel sorry for myself. I can't because there are so many people worse off than me. And I don't have to live with pain.
>
> I have days of self pity, but you know that that's what they are, a day of self pity and it doesn't do much good.

<u>Using Humor:</u>

Another coping strategy was to make jokes about the issues that worried some of the women.

> Like we reacted with humor. Like I have a good sense of humor...they'd say..."we'll put a radio-active sign on your door and we'll say 'if you don't pay, we'll send you back to see [Beth]'"... It's a bit sick; but, you know, what else could you do?

<u>Making sense of diagnosis and treatment:</u>

With the diagnosis of cancer come questions of why me? and why now? Most of the women offered some theory of why they had cancer.

> When the DES thing came out, that was of quite a lot of interest...because...my mother actually said...that she had taken some kind of drugs when she was pregnant.
>
> And I just felt that probably I didn't want to live because I really felt depressed at the time. ANd I feel that attitude was what started the cancer.
>
> I just look at it like something that happened to me. I guess it could happen to anybody. I don't know why. Doctors don't know why.
>
> Because I was living common-law and his wife died of cancer. And I often wondered if he...wasn't a carrier, eh? That really always bothered me.
>
> Well, first of all...you think about public toilet seats...And I thought that's ridiculous. And then I thought the pill...And then I thought to myself, maybe we've all got cancer and that's what started it off, more or less.

> I never thought I'd die. I figured...they cut it out and that's it and on we go...But never the less when my elbow got sore, that's the first thing that pops into your mind.

One interesting aspect of the theories was that the women generally did not check the theory with any medical source or any source that might disconfirm the theory. The statement from Hazel above suggests that she developed new theories after discarding previous ones.

> Everything that happened was more information; and every time information came in, you had to deal with it physically, intellectually and emotionally.

These women were searching for some ways to make sense of where they were and where they were going. What each woman had to face and how she coped with the process of treatment affected how she made sense of treatment. For those with complications the process of coping with physical symptoms and searching for causes went on for a long time after treatment.

Summary of Impact on the Self:

Redefining and defending the self:

Diagnosis and treatment for cancer required new roles for these women and challenged their sense of identity and definitions of self. Self concepts are developed through experiences of interacting with the world. Several of the women never experienced a major illness before cancer and found themselves interacting with the health care system in new ways. All of them had to confront the new role of cancer patient and the expectations that go with the role.

> Well he [the radiation oncologist] was quite gruff with me over not being there [sooner for her first clinic visit]: where was I at that point? And sitting in the [clinic] for four hours waiting wasn't pleasant either. Then when you're in there and they yell at you...that was disturbing.

In order to adapt to the role of patient and the loss of personal identity, one woman used a strategy of dissociation from the experience of pelvic examination.

> You get real used to being poked and prodded and feel like a piece of meat. And you just go, put your mind somewhere else, just get through this. Like you get used to having all your clothes off and everybody standing there looking at you like, 'so that's the specimen.' You go fine, I'll get through this, too.

In some instances the interaction with physicians invalidated personal perceptions. One woman felt she was put in a one down position when her physical symptoms were disconfirmed. She felt that her self-esteem was threatened, and she reacted with anger.

> I was accepting their incredible expertise. I had no expertise. So I didn't like being told, you don't have diarrhea...[and being] made to feel like an idiot or a nincompoop or a troublemaker or something when you bring up these problems.

Physical changes forced some women to re-assess their changing identities. One woman, who felt most valued as a mother, said

> I think the thing that hit me the most [about the cancer]... although I was going out of child bearing years, was that I could have no more children. I didn't want any more, you know what I mean, but...I think it's the mental aspect...when it's cut off like that...and that did hurt.

The women also experienced challenges to their ways of seeing themselves as a result of their interactions with their social environment. Their identities took on new aspects ranging from something like pariah to something like star status.

> And cancer is a bogey word anyway, so to know anybody who had cancer and they're still alive and walking and looking fairly normal - that's, people usually are just quite stunned.

The threat to the self increased the women's uncertainty, created a disequilibrium in the personal system, and created a need to regain some control and self esteem. The women did that by attempting to make sense of their experience and by seeking emotional support.

Phase II: Adapting and reclaiming the self:

The second phase begins when treatment ends. When asked if there were any milestones along the road to recovery several women remarked that the last day of treatment was the most memorable one. Therefore the impacts of the previous phase are the conditions of the beginning of this phase. The focus of phase II was on re-establishing normal lifestyle, accommodating changes, making sense of who they had become since their experiences with cancer.

> You have to deal with how your illness affects your day to day life. So you deal with all that before you can start rebuilding, before you can start being the new you as a person who used to be sick.

This phase also is broken down into two parts for easier description. The first part is "relearning your life" and the second is "looking to the future."

Contexts:

The three contexts - self, social and medical systems - continued to frame the experience of the women for this phase. Interaction between the women and medical system diminished while the women re-established their relationships with their social systems.

Part A: Relearning your life:

One woman used the metaphor of relearning her life to describe the tasks of getting back to normal, living with changes and making sense of her experience. The problem was to redefine what was normal for her.

Strategies:

Getting back to normal:

Several women spoke of the need to not let the experience disrupt their lives to any extent and to carry on or get on with living.

> I just dealt with the situation and carried on. I'd rather not dwell on past experiences. Once the treatment process was over, I closed the door and I never look back.

> I mean it's not going to be the most important thing that ever happened to me.

Another aspect of getting back to normal was the diminishing role of the health care system. Clinic visits became fewer and fewer. For many of the women the decrease in visits was a cue that they were doing alright. They began to have confidence in their bodies.

> Yeah, it's kind of a relief. First you go every month and then every three months... For some reason, to me, it felt like they were picking on me: I had to go more often than anybody else - which wasn't the case of course. It's just that you like to get it over with. And then when they finally told me a year, well that's a relief.
>
> I think even after my first year when I went back for my tests and...they told me I was fine, I kind of accepted it that way. But like I say it was nice going back all the time. It gives you more assurance going back there. You figure you have more confidence in them because if it's there, they'll catch it right away. I thought maybe I'd still be going there until ten years...but it [the seventh] was the last year.
>
> But eventually everything more or less settles down... you don't go to the doctor so often... I've adapted to what I can do and what I can't do.. Now I'm so much more normal.

Living with limits:

All the women experienced reduced energy levels after treatment, but most recovered their activity levels within a year or two after treatment. Some of the women returned to full time work all at once while others returned gradually.

> I started going back to work, but I was very very weak. I didn't think I could go back... I was still tired, really really tired and drained... But eventually I sort of worked my way in and I was full-time.

Most of the women indicated that there were on- going limitations to their sexual functioning. One woman reported that her sexual arousal was less:

> because for me it was real painful after. And then you've got that on your mind, the pain...And there's

> nothing really you can do about it because the doctor just says that you have to use the lubricant and that's it. ...[current sexual activity] probably not not not so often, no. And that's because there's still more pain than there was before but there's less than right after. But there's still more than before I had cancer in that area.

The two with complications had to adapt to some limitations that did not change. For one of them her definition of recovery meant having no more symptoms.

> And of course you have all these other problems; you don't ever feel like it's really over with. If they get rid of this bowel problem, then I'll feel it's over with.

Pushing the limits:

After recuperating from treatment or getting major side effects under control the women had to find out what activities they could do again. For some it was like regaining lost territory.

> When I got better, there's an interesting confidence thing that you have to deal with. Because you said no for so long that you begin to think well can I or can't I? And it is a relearning experience to be able to say yes I'll go to the bank after work: I don't have to save it up for two weeks in order to find enough energy to go. You have to relearn your life.
>
> And after you get stronger and stronger, you just do things different, too....your outlook: every morning you get up, you're alive and you're going to do the best you can.

Caring for self:

Learning to pay attention to how they felt came more easily to some of the women than for others. Some continued to worry about each new ache or pain, one had trouble differentiating the symptoms from chronic complications from what might be ordinary illness.

> I am certainly aware when anything physical is different about me. I wonder if this is because, or if its cancer. I'm probably more aware of cancer than I would have been otherwise.

> You see with my stomach the way it is, I never know if I have the flu or not....Worrying about it isn't going to help you. All you have to do is make sure you go to your doctor's appointments and checkups, take care of yourself.

> I never really know how I feel because I don't pay attention to myself. I put everybody else first and I come last...This is why I say it's so hard for me to go tell the doctor how I feel even when I'm feeling rotten. I really don't know how to explain and I just don't seem to get people to take me too seriously.

Making sense of surviving:

The women developed theories about how they had survived. Medical intervention predominated as an explanation, but religious faith, attitude and a sense of purpose were also mentioned as important.

> Thank God...that I got [cancer] in the 1970s and not in the 1950s. I mean thank God I live in a city like Edmonton and thank God [the radiation oncologist] is around.

> I believe that the Lord gave us our bodies and also looks after the repairs.

> Because I did pray. And if you have faith, that takes you through, carries you through. And my time wasn't there, it wasn't there.

> Your attitude, I think, is the biggest thing in your health. Not only that but your nutrition...your lifestyles and everything. So it's a real fight all the time to make sure that you're healthy in mind and body and spirit, too.

> I survived because I had to go on and do things. You got a family....You put them in the world so you got to try and guide them into the world.

Some of the women's beliefs about surviving appeared to emerge out of their beliefs about why they had cancer. For example, consider the first of the above quotations (starting on page 92) from a young woman who believed her cancer was caused by prescribed medication her mother took during pregnancy and her cure came from medical treatment. Contrast her beliefs with those of another woman who believed that her cancer was caused by her negative attitudes and she is cured as long as she maintains a positive attitude (fourth quotation above, this page).

Making sense of how they happened to have cancer and how they survived had an impact on how they considered their future health and well-being. An example of how such beliefs feed into current worries about the future is in a statement by another woman who believes that cancer is in all of us all the time just waiting for a trigger to start it growing. She cannot ever feel free from threat of cancer.

> I think I'm recovered but you've always got the fear in the back of my mind: I could have cancer in another part of my body somehow...But hopefully nothing is going to flare it off again anymore. I just pray and hope that it doesn't.

Impact on the self:

Reclaiming the self:

Another aspect of relearning their lives was for the women to re-establish their own sense of identity. For some the task was relatively easy because they had felt no great threat to their self-esteem.

> I was happy before the cancer and I am happy now. I am a fortunate person and find that I am not any different than I was before the cancer.

For others the challenge was greater and meant holding on to their sense of self in spite of losses and in response to others perceptions of them.

> I was able to hold on to many of the things that are me.

> [Regarding infertility:] this is what I am, and I guess I'm quite a lot. This has nothing to do with cancer: it has to do with me. I mean I think I know who I am and what I'm all about, and this is the package. So if you don't fit in this package, then I guess that's okay.

Part B: Looking to the future

Condition:

Re-assessing quality of life:

Generally the women rated their current quality of life as satisfactory to very good. In talking about their criteria for good quality of life, the women most often mentioned their relationships with their spouses, children, other family and friends as important. Not surprisingly personal health was also an important criterion.

> What makes life worth living? Well, family and what you can do to help others less fortunate... Just being

> alive and being able to look at my husband and see that he's all right... I don't really care for material things anymore, they don't mean a thing to me really. Sure its' okay to have a home. But actually if the other half of your life isn't here, its not important, nothing is important.

> It's made up of a whole whack of things like friends and family are important. And I certainly think that just as I've gotten older I've come to appreciate them more. Partly because I'm single, I'm sure.

> With cancer, it's enriched your life, I think, as far as not taking life for granted. Quality of life: you need health, definitely health to keep you going. [Before cancer] I took my health for granted...You know: you're doing the right things in life, so why shouldn't you be healthy?

For the three above, there were clearly changes in their criteria for good quality of life. Other women also mentioned the desire for opportunities to help others and to learn.

> It's just going back and living your life to the fullest I guess... And learning about, like we went on that trip. I like going on trips to learn other people's culture: how they live, how we live. I really like learning, just the learning process.

The two with complications said there was some lessening in quality of life in the areas affected by the complications. They also found areas of their lives that they rated as having good quality.

> That when everything I did had to be weighed and measured, that wasn't quality. Never being able to say yes I'll come and enjoy myself: I'll go to the show. Even now I can't go to a movie and be sure I'll get through it without having to [go to the washroom]. All of those little things, you just get tired of thinking of them. As far as quality of life in terms of your home and everything, I have a job that allows me, I'm well enough to do the job, and I can buy the things I want. I can be comfortable in my

> surroundings. I'm close to my family and that hasn't changed. That quality is high.

It also was clear that there were other life experiences that influenced their assessments of their quality of life.

> I don't know it's just the way I am I guess. I really have nothing against life. You know I've got a [relative] who committed suicide. Now maybe that's got something to do with my reaction to life... We realize that nothing can be really that bad that you have to give up your life.

The women assessed their quality of life in comparison to what they had experienced before and since cancer and in comparison to others around them.

Strategies:

Living with changed priorities, goals and time frame:

As in previous studies of long term survivors (cf. Kennedy, Tellegen, Kennedy & Havernick, 1976), many of these women experienced changes in their priorities and goals. Also their focus on doing the things that are important to them now was noticeable.

> I don't know whether it was the break from work or whether it was being faced with your own mortality.... I don't think I'm as ambitious as I used to be. I just changed; my priorities changed. I just decided that friends were more important than I had given them credit for before.

> Well now I feel I want to educate myself a little bit more or even help people a bit more...In fact I've even thought of doing volunteer work at the cancer hospital...whereas before [my attitude was one of] helping people if they come along your way but you don't put yourself out.

> Don't put it off just do what you have to do... Actually, you find that life is very precious when you

> go through experiences like that. Live your life and make sure you just got your life ready at all times... You could drop dead.

These women recognized that they had made some subtle shift in what they valued and how they saw life. Although they did not see themselves as really different from before their cancer experience, it just made sense for them to do things a little bit differently.

Handling fears of recurrence:

How the women assessed their chances of recurrence appeared to be a direct result of how they understood having had and been treated for cancer. For example contrast Hazel who continues to worry about something triggering the cancer with Karen who believes that God healed her and does not worry about having cancer again unless it's God's will.

They were asked how they would react if they had a recurrence of cancer. Some said they would make sense of it the way they did before, others said they would have to re-think their ideas about how they were cured.

> It would kind of throw all my theories out the window. I think about that sometimes: is what I believe real or is it just something that is sort of latched on to because it sounds good... I thought I had covered all the bases to prevent myself from getting it... I would probably have to search for something else or maybe it's just past control anymore because of the environment or lifestyle or something.

> Most things you do get better at, but sickness you don't get better at. As you get older, you're less prepared to think that you're invulnerable.

> Probably it would be easier for me to cope with, I would think, because the main shock of finding out you have cancer, I think that's something that you'll never ever have the second time.

Facing normal aging:

Some of the women talked about how they had changed their perceptions of growing older. Perhaps the experience of cancer gave them an opportunity to face their feelings about aging. Some had increased worries and some a sense that they could handle aging better than their peers.

> I'm finding it really hard because, of course, I'm getting older. And I'm just wondering, too, because of the radiation treatment, that if, like in the early onset of menopause, that my body is probably slowing down quicker maybe than others.

> The older I get, probably the better off I will be. When other people are just encountering their own limitations and vulnerabilities and things, I'll have already dealt with that. So I can carry on at that point.

Telling the story - Helping others

Through telling the stories of their experiences the women were able to reassure others and themselves that cancer is survivable. They wanted to convey to other women that it is possible to come out of the experience alive.

> Definitely be positive and look into the future... There's other people that have gone through it, and you will definitely get through it... In fact... my daughter got on to me and said would you write [daughter's friend who had gynecological cancer] a letter? So actually in the letter I did write something to that [effect]... A few months later she wrote back, and she was very very thankful for it.

Telling the story gave the women opportunities to further understand and validate their own experience and enabled them to help others.

> I told [my children]. They'd sit there and listen to me. Oh yeah, its the same as my brother or my sisters, they wanted to know everything too. There's nothing hiding you know. I wouldn't in case they had to go through it some time too.

> I've talked to different women who have had hysterectomies. And after listening for a long time, I might say something about, well, I had a hysterectomy; and it might go from there. But people's reaction is always amazement because I'm young and healthy looking.

Impact on the self:

Becoming a model:

Sharing with others the fact that they had survived cancer was a crucial part of how the women made sense of their survival. They had changed their perceptions of cancer from meaning certain death to being a survivable crisis. Their own survival was important as a model for others who might face the same crisis.

> And I probably will live to be a 120. I can be one of those statistics. Actually, that is one of those things that gives me a certain amount of satisfaction. I'm one of those statistics. I'm one of the people who will give some poor soul down the way confidence. And they'll say, "Well this woman had cancer when she was 28, and now she's 72, and she's healthy enough." So some person who is sick then can say "Well look, she lived 50 years; I can do the same."

Chapter VI: DISCUSSION OF THEORY

A significant recurrent theme that emerged from the data was impact on the "self." The informants talked about how they saw themselves changed during and after the cancer experience. They described unusual experiences of self. For example, one mentioned putting her "self somewhere else" during an embarrassing medical examination. Another said she had to learn to see herself as a healthy person who used to be sick. They expressed their impressions that others saw them variously as "numbskulls", "inspirations", "lepers", or "invalids". They spoke of the influence of others as significant in how they saw themselves.

These and other references to self suggest that there is an interaction between their experiences with cancer and their self-concepts. The self about which the women spoke was one which was consciously available to them and about which they had thoughts, a concept of self.

It is interesting to note that the literature on survivors of cancer says very little directly about the self or self-concept. Several articles mentioned in the initial review of literature mention self-esteem and self-image which both imply something called a self (cf. Andersen & Hacker, 1983a, Mages & Mendelsohn, 1979, Krouse, 1985). Therefore, it was necessary to go to the literature regarding the self for further understanding of this concept.

It must be noted that a secondary review of literature that follows data gathering in grounded theory research differs from the review of literature that precedes more conventional research. The latter has the purpose of identifying hypotheses that will be tested in the research. The secondary review of literature in a grounded theory study has the purposes of 1) providing further data to supplement the data collected in the study and 2) providing comparisons for theoretical concepts that emerge from the data.

The following discussion emerged from a review of literature pertaining to self theories. The purpose was to clarify the interrelationships between self-concept, social interaction and making sense. The review focussed on a small subset of the literature on personality, identity, and social role that appeared to be most relevant to the concerns of the women in this study.

Several questions guided the current review of literature: What is the nature of the self-concept? How is self-concept developed? Rogers (1951), Mead (1934), Kelly (1955), Hilgard (1949), Watkins (1979), Epstein (1973), Cashdan (1988) and Mahoney (1985) -- were all searched for insight into these questions. What effect does cancer have on self-concept? How does a significant social interaction in a traumatic event affect self-concept? What is the relationship between self-concept and making sense of an experience? Thompson (1981), Taylor (1983, 1989), Taylor and Brown (1988), Maher (1982), Moos (1982, 1986), and Figley (1989) -- were all searched for insight into these other questions.

The Nature of the Self-Concept

In the following proposition, Rogers (1951) dealt with the nature of the self-concept and how it might develop:

> As a result of interaction with the environment, and particularly as a result of evaluational interaction with others, the structure of the self is formed -- an organized, fluid, but consistent conceptual pattern of perceptions of characteristics and relationships of the "I" or the "me", together with values attached to these concepts (p. 498).

Rogers viewpoint is consistent with that of George Mead who suggested that the self concept develops through social interaction. It also appears to be consistent with George Kelly's view that "man looks at his world through transparent patterns or templets which he creates and then attempts to fit over the realities of which the world is composed" (1955, pp. 8-9).

> The self, says Hilgard, is in part an organization of the largely interpersonal motives and attitudes that are of central importance to the person, and which persist and remain recognizable as the person ages. (Lazarus & Folkman, 1984, p. 79)

These various definitions of the self suggest that the self has both stable and developing dimensions. These two dimensions are important for understanding how the data from this study have been arranged. Self has been presented as a framework for managing new information (the stable component) and as being influenced by the events and interactions experienced (the developing component).

Several theorists have expanded on the organization of the self to include sub-systems or a hierarchy of constructs or systems. Watkins (1979) calls these sub-systems of the personality "ego states" and uses them to explain dissociative experiences. One woman in the study described a dissociative experience as follows:

> You get real used to being poked and prodded and feel like a piece of meat. And you just go, put your mind somewhere else, just get through this. Like you get used to having all your clothes off and everybody standing there looking at you like, 'so that's the specimen.' You go fine, I'll get through this, too.

Kelly (1955) and Epstein (1973) both conclude that the structure of the self is a subsystem of internally consistent concepts contained within a broader conceptual system. Epstein compared and integrated the ideas of several theorists (including Mead, Hilgard, Rogers, and Kelly) and proposed that the attributes of self-concept were the same as of a scientific theory and that the self concept was in fact

> a theory that the individual has unwittingly constructed about himself as an experiencing, functioning individual, and it is part of a broader theory which he holds with respect to his entire range of significant experience. (1973, p. 407)

Consistent with these views, some of the women presented a "working theory" of who they are. For example:

> I'm not the kind of person who makes crises out of things. Like you just say that this is the way it is,

> deal with it, and get on with life. (For other examples see page 70).

According to Epstein the basic functions of a self theory are "to optimize the pleasure/pain balance of the individual over the course of a lifetime", "to facilitate the maintenance of self-esteem, and to organize the data of experience in a manner than can be coped with effectively" (p. 407). Epstein also said that

> The need for people to defend desperately certain concepts or values, no matter how unrealistic they are, can be comprehended readily once it is recognized that a self-theory is necessary in order to function, and that any theory is better than none. (p. 416)

The necessity of having a theory about some aspect of self is reflected in the following comment by one of the women in the study when she talked about what would happen if she had a recurrence:

> It would kind of throw all my theories out the window. I think about that sometimes: is what I believe real or is it just something that is sort of latched on to because it sounds good... I thought I had covered all the bases to prevent myself from getting it... I would probably have to search for something else or maybe it's just past control anymore because of the environment or lifestyle or something.

Development of the Self-Concept

As noted earlier, the "self" has a developmental dimension as well as a stable dimension. Rogers postulated that the development of values is influenced by "conditions of worth" (other peoples' expectations and evaluations). Rogers believed that the conditions of worth set up incongruence with actual personal experience and that the developing individual would compartmentalize experience as acceptable and non-acceptable and remove the latter from conscious awareness.

Several other theorists explore the development of polarized values and "splitting" self into good and bad components as influenced by the primary caretaking relationship in infancy (Cashdan, 1988, Mahoney, 1985).

Cashdan explores "splitting" in the context of "object relations" theory which sees the split first in terms of mother being split into good and bad mother in relation to the child. The split perceptions of mother are then incorporated into the child's own perception of self as a good self and a bad self. He said

> We become our "other" by incorporating significant others and psychologically transforming them into self. (p. 47)

In the adult phase of self/identity development, Cashdan integrated the ideas of "symbolic interactionalism" (cf. Mead, 1934) as the natural extension of object relations theory. And like Watkins, Cashdan sees the self as a series of subselves or self-other systems or identities, each subsystem being activated by social circumstances relevant to that system.

> Much of adult life involves establishing relationships which will enhance these identities. To the extent that each is a part of the self, the process contributes to one's overall sense of "self-worth."(p.51).

Rogers (1951) described the process through which new experiences are incorporated into the fluid organization of the self-concept (as mentioned earlier):

> As experiences occur in the life of the individual, they are either (a) symbolized, perceived, and organized into some relationship to the self, (b)ignored because there is no perceived relationship to the self-structure, (c) denied symbolism or given a distorted symbolization because the experience is inconsistent with the structure of the self. (p. 503)

The values attached to experiences and concepts affect how subsequent experiences are perceived and included or not included into the organization of the self. In other words some experiences are considered "not self" and therefore are ignored, denied or distorted. Kelly also notes the human tendency to order experience into likenesses and differences (1955, p. 52). Therefore it would be interesting to consider where cancer, a disease that appears to originate within the body, would fit into the continuum of self and not self.

Impact of Cancer on Self-Concept

A life threatening illness has the potential to alter the way an individual sees the self. Although the women in this study did not perceive themselves to be totally different than they had been before the cancer, they did take in new information about themselves.

> [In the beginning] you're very threatened: the 'you' is threatened, the essence of you. Everything that you know about you is changing. It's being swept out from under you, and you don't know what is going to happen.

The question arises as to how cancer is seen in relation to the self. Lockhart (1983) related the story of a patient who told him that "he experienced his cancer as consuming him. Then he added: 'It's more than that. It's like I'm consuming myself'" (p. 67). For that patient the cancer was a part of himself that was destroying himself. Perhaps some patients experience the disease as a loss of integrity or as if some part of themselves was betraying the whole.

However, a radiation oncologist at the cancer clinic remarked that patients often are unsure that radiation is sufficient treatment and say "can't you just cut *it* [meaning the cancer] out?" For them the cancer has been defined as "not self."

One of the informants in this study said she thought that cancer was something that was always in us and that it only needed a trigger to become malignant. Her belief about cancer appears to fall somewhere between self and not-self. In any case, cancer seems to be different from other illnesses where the causes are clearly "out there".

Furthermore, there is documented evidence that the effects of cancer and treatment can alter the physical body which in turn alters the body image (Andersen & Jochimsen, 1985, Schain, 1981, Sewell & Edwards, 1980). The body self is a subsystem of the self-concept (Epstein, 1973, Cashdan, 1988). Cassell (1982) tied the changes in body to the experience of "not self":

> Disease can so alter the relation [with one's body] that the body is no longer seen as a friend but, rather, as an untrustworthy enemy. (Cassell, 1982, p. 643).

Because the self-concept is mutable and the impact develops over time, it is reasonable to look at phases in the process. The sequential phases that are used to organize the data from this study are analogous to the stages or seasons described in Fitzhugh Mullan's "Seasons of survival" (1985). His central theme is that, rather than seeing cancer patients as either ill or cured, it is more useful to consider them in some stage of survival from the time of the diagnosis onward. He also suggested that seeing oneself as a survivor makes a difference in how one perceives one's situation.

His model has three stages or "seasons": acute, extended and permanent survival. Acute survival covers the time from diagnosis through basic treatment when life is focussed on involvement with the medical system. In this study "phase I" is equivalent to Mullan's season of acute survival.

Mullan's season of extended survival focussed on adapting to the physical changes and to changed roles at home and at work. His focus on adaptation parallels the experience of the women in this study in regard to the first part of phase II: "relearning your life". He noted that the experiences of people in this period "are as varied as their diseases, their adaptability, and their home and work situations" (p.272). In some sense the season of extended survival could apply to most or all of the women's experiences as shared in their interviews.

Mullan suggested that there is "an evolution from the phase of extended survival into a period when ....the cancer can now be considered permanently arrested" and therefore the line between extended and permanent survival is not clear (p. 272). The data from this study did not support the existence of a clearly differentiated third phase, so the categories of experience are divided simply into the two parts of phase II.

Impact of Significant Social Interaction on the Self-concept

When the women came to the cancer clinic for the first time, they described their encounters with the attending physicians as significant to their experiences. At least eight of the women met the same female radiation oncologist on their first visits. One woman met a male radiation oncologist on her first visit. Her experience contrasted with that of the other women. It is hypothesized that in the illness experience, the physician represents a significant other.

Interaction validates or violates self-concept:

Consistent with the importance of the 'self-worth' issues, the role of the physician seems crucial to the experience of being validated or violated. The majority of informants identified their encounter with the radiation oncologist as important to how they felt about going through treatment and regained a sense of hope for a positive outcome. The physicians treating them with respect appeared to support their sense of importance, capability and self worth.

Several of the women described meeting the radiation oncologist as positive because she treated them as "intelligent human being[s]" and remembered them individually over the years. Their sense of self-worth, significance and competence was affirmed by her behavior. The one woman in the study, who first met with a different physician, said that he treated her symptoms and concerns as invalid or trivial; and she felt diminished in her self-esteem.

One could speculate that the interaction with the physicians during the highly charged events around beginning treatment have greater potential for impact on self-concept than ordinary interactions have. The diagnosis of cancer means a new identity as cancer patient. The attributes of that new identity develop through interaction with the medical system and may focus on the attending physician. Cashdan (1988), in describing the development of identities, stated that

> Identities, in the last analysis, are essentially subselves. They are constructed out of relationships and rely on relationships to remain viable. This is why relationships are so critical for psychological survival. They fuel and sustain the different identities that make up the self. (p. 51)

The interaction with the physician not only gave the women information about their changed or expanded identity or self-concept, it also gave them information relevant to predicting their future experience.

Interaction provides information about the future:

There have been several studies that indicate that information about procedures may be important to patients in managing their experience and predicting the future (Johnson, Lauver, & Nail, 1989, Suls & Wan, 1989). It is therefore not surprising that the radiation oncologist, who saw most of the women was highly valued by them. In a collateral interview, this physician described her first session with new patients with cervical cancer. She said that she takes the time to draw a picture of the abdominal organs and to explain very carefully how the cancer will be treated. She gives details about the procedures and consequences and thus makes the experience seem more manageable and survivable.

Perhaps we must assume a meta-process is occuring in the information sharing. As the women gain information about their current environment, they can begin to establish trust in the medical system. They learn what to expect, and that information helps them decide whether treatment makes sense to them or not. The information gives them a sense of control.

Thompson (1981) suggested that the need for information relates to the need for control by enabling one to predict potential dangers. She presented Miller's minimax hypothesis which states that:

> having control in a situation indicates one will be able to minimize maximum future danger....According to this hypothesis, information will also be effective to the extent that it reassures people that the sensations they will experience will not be unbearable. (p. 97)

Thompson further suggests that people seek information about three dimensions of experience: endurability, desirability and whether it is planned or not. Probably the first dimension considered by someone facing treatment for cancer would be whether the experience can be expected to be endurable or not. If the experience is endurable, then she wants to know if the outcome will be desirable or not. Finally people need to know whether the experience is planned or arbitrary. In order to maintain a belief in an orderly meaningful world, it is necessary to find some reason that events happen. For example to say 'God planned this as a learning experience for me' provides both a sense of meaning and a possible path through the experience. Thompson noted that

> ... those experiencing a misfortune look not so much for a sense of control as for a sense of meaning, a need to perceive an orderly and meaningful world (p. 95).

Thompson also sheds light on the question of patient participation in decision making. Researchers typically associate the need for information with the desire to have control over treatment decision making. Degner and Russell (1988) state the problem in the following way:

> The consumer movement is fostering an assumption that most people desire some degree of control over treatment decisions which will influence their survival and quality of life (p. 367).

The women in this study said that they did not want to make decisions about treatment once they were confident that their physician was competent. As Thompson said,

> When control in the hands of another person is seen as minimizing future danger, such as a skilled professional administering a hypodermic, then less personal control will be preferred... One would predict, then, that reactions to stressful events, depend not only on the patient's personal sense of control in the situation but also on their perceptions of the interests and intentions of those who are in charge of the events. (p. 97)

Relationship between Self-Concept and Making Sense

The two aspects of the interaction with the physicians described above -- validation of self and information about the future -- are interrelated. If we accept the view that the "self" is a theory about the world and one's relationship to it that includes a set of schemata around which new information is organized, then "making sense" becomes the vehicle for organizing new information and building expectations about the future. Making sense could be thought of in terms of attaching meaning to events in order to make them more manageable and accommodate them into the pre-existing theory of self.

This concept is most aptly considered in the theory of cognitive adaptation to threatening events proposed by Shelley Taylor (1983).[1] Taylor's theory was based in part on studies of women with breast cancer. She argued that:

> when an individual has experienced a personally threatening event, the readjustment process focuses around three themes: a search for **meaning** in the experience, an attempt to regain **mastery** over the event in particular and over one's life more generally, and an effort to enhance one's **self-esteem** -- to feel good about oneself again despite the personal setback (p. 1161).

Taylor described meaning as "an effort to understand the event: why it happened and what impact it has had." She suggested that "the specific form of the cognitions patients hold about their illness may matter less than the functions those cognitions serve."

> Moreover, specific cognitions (such as attributions, beliefs about control, or social comparisons) are in some cases functionally equivalent or at least functionally overlapping. The need for self-enhancement can conceivably be served by believing one has control or by making downward comparisons. Likewise, the need to find meaning in the experience can be served by finding an explanation for the event or by laying out a plan for controlling things in the future (p. 1167).

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[1] See also Moos (1986) who developed a list of adaptive tasks for coping with life crises that included "establishing meaning," "preserving satisfactory self image" and "maintaining a sense of competence and mastery" (p. 11).

Taylor found that when cancer patients' theories about causes or control of cancer were disconfirmed, they simply substituted another theory.

> If one's belief about the cause of one's cancer is disconfirmed, one finds another potential cause to satisfy one's search for meaning.... People often hold multiple or serial theories about their cancer that would seem to have vastly different psychological consequences, but which apparently do not. Moreover, having one or more theories disconfirmed does not seem to be particularly bothersome (p. 1170).

An example from this study was be the woman who first believed that she got cancer from a toilet seat and then shifted to a belief that cancer was inside her all the time just waiting for a "trigger" without apparent difficulty.

Thompson (1981), mentioned above, supported the importance of assigning meaning to coping with misfortune because research suggested that:

> Reaction to a misfortune seems to depend in part on the meaning assigned to the event, and seeing oneself as causing the event is one way of making sense out of it. (p. 96)

Thompson's suggestion may shed light on the prevalent idea among patients that they caused their cancer by their attitudes. One woman in the study who took the positon that her negative attitude had caused her cancer appeared to be constantly vigilant against the reappearance of those attitudes that might be injurious to her health. In contrast the woman who took the positon that God had healed her cancer (and knew why she had it in the first place) appeared to be free of constant worries and vigilance. She felt she knew what to do if she had a recurrence: trust in God. The difference between these positions seems to be consistent with Thompson's conclusion that the challenge is to discover:

> the types of meaning that can be used and to explore how to help individuals develop the ability to assign meanings that will be the most beneficial to them. (p. 99)

One coping strategy that Taylor identified in her study of breast cancer patients was downward social comparison, i.e. comparing oneself to a less advantaged person, as a means of reducing self-pity and restoring self-esteem. All the women in this study found some person or circumstance that was less advantaged. They volunteered statements that began " I could not feel sorry for myself because..." and described a comparison group such as children with cancer or people who were crippled and dying.

Taylor suggested that downward social comparisons and ideas about causing one's own cancer were based on illusions the individual maintains. Taylor found that the breast cancer patients, whom she studied, commonly believed that their personal coping abilities were extraordinary and they could personally prevent the cancer from coming back, even when recurrence was likely. In a recent article Taylor and Brown (1988) expand upon the adaptive value of such illusions as "unrealistic positive self-evaluation, exaggerated perceptions of control or mastery, and unrealistic optimism" (see also Taylor, 1989). A positive bias in perceiving reality becomes most apparent in situations of threat and importance to the self. In coping with circumstances of adversity:

> the belief in one's self as a competent, efficacious actor behaving in a world with a generally positive future may be especially helpful in overcoming setbacks, potential blows to self-esteem, and potential erosions in one's view of the future. (p. 201)

The data from the present study are consistent with Taylor's finding that beliefs about positive self-worth, control and optimism contribute to adaptation in crises. The process of maintaining the self describes how the women integrated the experience of cancer into their self-concepts by using existing beliefs and creating new beliefs to change their views of self. Making sense is the process of adapting old and new beliefs into the developing self-concept.

The relationship between self-concept and making sense also can be looked at from the perspective of maladaption as in Maher (1982) article on the "anomic aspects of recovery from cancer." She described anomie in terms of Durkheim's model of societal anomie, or meaninglessness. Durkheim's model has four elements: (1) a social condition, (2) the product of a crisis, (3) a crisis that may be either malignant or beneficent, (4) out of which grows a climate of uncertainty and indeterminancy. Maher focused on the fourth element as "an attack on the nomizing or meaning-giving power of society." She referred to Berger and Kellner who state that anomie

> consists in the disruption for an individual of "the sort of order in which he can experience his life as making sense," an order which they regard as inherently fragile and constantly in need of validation by significant others. (p. 910)

Maher proposed that while being diagnosed with cancer is a crisis with which people are prepared to cope, that surviving cancer may be perceived as an unexpected although beneficient crisis. Because their orientation has been to stay alive and focus on the moment, survivors may have difficulty in shifting to focusing on a future where they will be most assuredly alive. They have lost the immediate goal of surviving and not yet replaced it with further goals. They also may have lost social validation at a time "when the need of reestablishment of identity is the greatest, when the ambiguities of the situation are least understood" (p. 912).

Maher further noted that some patients are reluctant to terminate clinic visits because of the loss of social support offered by the medical system and loss of security of being treated by the "experts". These losses can lead to the experience of disorientation and meaninglessness for the cancer survivors at a time when they expect to be happy.

The data from this study did not add much support to Maher's findings. At least one woman in this study mentioned that she was sorry that she no longer had annual visits to the cancer clinic. She said that she felt more secure going to the clinic because she thought that if her cancer recurred the oncologists would respond more quickly than her previous physician had.

However, generally the women did not describe the end of contact with the cancer clinic to be a difficult time. Some of the women were being followed by the clinic at the time of their interviews, and the interviews may have been seen as part of the extended follow-up. A question arises about the possible benefits of an interview at the time of the last follow-up visit at the clinic visit in bringing closure to the experience. Perhaps further research would provide answers.

One more area of research that appears to be relevant to this study is Charles Figley's work on families and post-traumatic stress syndrome. Figley (1989) presented a model of adaptation to stress by family systems. His work is relevant to this study because he noted that the impact of traumatic events is felt long after they are over. Whether the individual considers the diagnosis and treatment of cancer traumatic or not, it is clear that all the women interviewed considered the experience something they wanted to discuss long after it was over.

Figley said that in the long term process of adaptation the traumatized person will go through phases where they do not want to talk about their experience. One possible reason that two women chose not to participate in this study was that they were in such a phase where they were not ready to reconsider and discuss those experiences.

Then, according to Figley, some triggering event will stimulate recall at a time when that person may be ready to re-examine the experience in order to resolve the feelings around traumatic events.[1] Figley proposed that the individual or family would need to develop a

> "healing theory" that fully accounts for what, why and how it happened and why they acted as they did. ...It is a set of statements about the circumstances and consequences of the trauma for the family and an optimistic scenario of what would happen if a similar traumatic event took place again. (pp. 64-65)

What Figley called a "healing theory" appears to be the process of making sense that the women in the study used to maintain their sense of self. Telling the story of the experience maybe an interactive way of developing a healing theory. In that sense the interviews provided opportunities for the women to explore their theories about the experience and integrate them further into their self-concepts at that point.

Finally, in this chapter, the criteria for evaluating a substantive theory will be applied to the theory of maintaining the self.

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[1] Wortman and Silver (1989), in their review of literature on grieving, question whether every loss (and by extension trauma?) needs to be "worked through" to resolution.

Criteria for Evaluating a Substantive Theory

Glaser and Strauss (1965) suggest that a "grounded" theory must have four attributes in order to be a worthwhile theory: fitness, understanding, generality, and control.

Fitness: Fitness describes how closely the theory relates to the "daily realities" of the substantive area. The process of maintaining the self emerged out of the narratives of the informants as a main theme in their experiences. When the process description was presented to one of the informants, she said that the elements of the theory reflected her own experience. And when it was presented to three other people who have had life threatening illnesses (e.g. polio), they found the process relevant to their experiences. The researcher also found the concepts to be relevant to the experiences of other cancer patients who were seen at the clinic.

Understanding: A theory must be meaningful and usable by people working in the substantive area. The preliminary results of the study were presented to the Canadian Association of Psychosocial Oncology Conference in April 1989. Although the main theme has shifted from "making sense" to "maintaining the self (through making sense of the cancer experience), the process that was described has remained the same. Several healthcare professionals who heard the presentation said they had no trouble understanding the process that was described. They thought the theory made a meaningful contribution to their understanding of cancer patients. Since then the results have been presented in more complete form to the Alberta Cancer Board Annual Research Meeting in November 1989. Several nurses and physicians said that they could see how the concepts could be applied to their clinical areas.

Generality: A theory needs to have flexibility to apply to changing situations and to be modifiable when it does not work. The process of maintaining the self would most likely apply to other circumstances where people face threats to their self-concept and self-esteem. The substantive codes that are described in the chapter on process are specific to the circumstances of women who survive a life threatening illness. However, the theoretical codes that represent the links between the substantive codes would apply to other adaptation to crisis situations. The issues, events could alter without the basic process of maintaining the self disintegrating.

Control: A useful theory offers greater control over every day situations through its application. At the most basic, a theory should help people in the substantive area to understand and analyze ongoing situations. Beyond that it could help them to produce and predict change in the situation and to predict and control consequences. A pediatric oncology physician at the ACB research meeting said that he could see how important his initial visits with parents of pediatric patients were. He said he had learned to be careful of the manner in which he presented information because he could see the impact on parents' compliance with medical procedures as time went on. His clinical experience paralleled the information the women in the study gave about their experiences.

Already the theory developed in this study has helped psychologists at the cancer clinic to ask better questions of their clients. They have become alerted to the significance of patients' theories about themselves and their situations and have begun to explore these areas in their counselling work.

Chapter VII: CONCLUSION AND IMPLICATIONS

The information gained in this study contributes to our general understanding of the long term psychosocial effect of surviving cancer. It also underscores the importance of the physician-patient relationship at the time of diagnosis, and provides a perspective on some key issues that women with cervical cancer have to handle in their long term recovery.

The fundamental issue seems to be the patient's sense of vulnerability as she faces the potential dissolution of self that can result from the multiple challenges of having a potentially life threatening condition. The long term survivors in this study had learned to counteract that fear by finding ways to maintain their sense of self even in the face of this challenge.

Reflections on Potential Bias

As discussed earlier (see pages 47-48), the researcher was aware of the potential influence of her background and frame of reference on the data presented by the informants. First of all the researcher thought that the experience of surviving cancer might be a significant existential issue in the lives of the women. However, while it was implicit in the research design that the experience of recovering from cancer had long term effects on the lives of the women in the study, the researcher initially underestimated the clarity and intensity of the recall of certain moments in the experience. It was clear that even ten years later these events had a great deal of impact on how these women viewed their experience and how they viewed their current lives. The women were unanimous: their encounter with cervical cancer mattered.

Related was the assumption that in facing the challenge to their existence they would be grappling with the existential meaning of their lives, but this did not turn out to be as dramatic or as clearly differentiated as the researcher had first assumed. Rather, research findings showed that the women each developed coping strategies and ways of maintaining the self based on the way they made sense of their circumstances over time. While their search for some kind of meaning in their experiences contributed to the process of maintaining the self, the data suggested that "making sense" was less of a sudden revelation and more of a cumulative process and as often focused on daily living issues as it did on "meaning of life" issues. This contributed to the hypothesis that rebuilding the sense of self takes many small steps and occurs over a long period of time. This process is called "maintaining the self."

Several other assumptions were modified based on the emerging research. The researcher, for example, originally emphasized the patient's attitude in the recovery process; but the study findings sharply pointed to the need to examine the physician's attitude as well, especially at the moment of diagnosis. Without prompting, the informants contributed vivid and detailed information on the encounter with physicians around the time of diagnosis and the subsequent discussion of treatment options at the cancer clinic. The women reported being influenced strongly by two factors: 1) how the physician communicated and 2) the quality of the information. These findings contributed to a heightened awareness that 1) the attitude of the physician is very important (i.e. whether she or he is confident and respectful) and 2) the content of the message is crucial (i.e. does it enhance the woman's capacity to anticipate her experience and regain a sense of control). Even ten years later, the women could remember such details as the expression on the physician's face and whether or not she felt respected.

Further, the researcher thought there might be a relationship between psychosocial developmental issues such as trust, autonomy and intimacy and how the women adapted to their experiences. However, only one issue stood out in the narratives concerning the initial challenge to the self. The relationship between loss of control (due to the threat of death) and the ability to effectively gain information about her prognosis emerged as a crucial element in maintaining the self. The process of information transmittal seemed to help (or hinder) each patient in regaining a sense of control much more than the study could have anticipated. The issue of control/helplessness turned out to be not only common to all of the respondents, but far more important than originally assumed. The women in the study reported a strong parallel between regaining their sense of control (and their self-esteem) and their confidence about having accurate and timely information. Even if they could not control the onset of the disease, they could substitute an ability to predict its course.

Limitations

It is important to keep in mind that the informants were selected on the basis of theoretical sampling. The purpose of the interviews was to identify relevant variables and a basic psychosocial process that might be relevant to other cancer patients. The results of this study are a reflection of the experiences of the women who participated and cannot be generalized to other groups without further research.

In addition to the potential sociocultural bias introduced in the selection process, the choice of cancer site also limited the kind of data given about their experiences. The particular cancer with which these women were diagnosed tends to affect a small part of the body in contrast to the lymphomas or germ cell cancers which have more global physical effects and are also survivable.

Clearly the process of maintaining the self would have to be studied with other samples before a formal theory about survival could be developed.

It cannot be assumed that all cancer patients or even all cervical cancer survivors would want to talk about their experiences. However, it is noteworthy that only two women declined to participate on the basis that they did not want to talk about their experience. There is no evidence whether willingness to talk about the experiences is a reflection of the characteristics of the women interviewed or an indication that they have reached some stage of adaptation where telling the stories is meaningful to them.

Although the researcher made every effort to allow the informants to tell their stories in their own ways, it must be noted that the introductory letter and the consent form were typed on cancer clinic stationery. The researcher probably was seen as a representative of the cancer clinic, a perception that may have influenced the direction of some of the women's narratives. Further studies by other researchers might shed light on this possible source of data distortion.

Further, the fact that 80% of the women saw the same radiation oncologist may have influenced the results. The degree of experience and expertise, medically and psychosocially, of the attending physicians at the cancer clinic may have been a factor in minimizing the trauma experienced by the women in this study. This is certainly an area for further research.

Conclusions

The experience of recovering from cancer had long term effects on the lives of the women in the study, especially on how they maintained their sense of self when confronted with their new identity as a cancer patient. They felt vulnerable and uncertain about the future; most of them felt threatened with dissolution and death. Even years later those events still had significance and the potential to provoke a strong emotional response in the women when they were recounting their experiences.

The evidence suggests that the experience of having cancer presented a strong challenge to their sense of self. In order to adapt in a crisis situation, these women expressed a need to make sense of their situation, to regain a sense of control and to enhance their self-esteem. These are all aspects of maintaining the self.

While few recounted dramatic revelations about their lives, for most the experience led to a better organization of self in the sense of changed priorities and greater appreciation of life. Their lives changed in subtle, but meaningful ways. One of the women described it this way:

> I don't know whether it was the break from work or whether it was being faced with your own mortality.... I don't think I'm as ambitious as I used to be. I just changed; my priorities changed. I just decided that

> friends were more important than I had given them credit for before.

The study found that long after the treatment was over, the women were still adapting to the changes they had experienced. Even ten years later some of them were still sorting out the meaning of their experience and how it affected the way they saw themselves. Telling about the experience was an additional step in the process of maintaining the self. The interview provided an opportunity for the women to review their experiences in order to gain a better understanding of the events and the impact these had on their lives.

For each woman, the effects of the cancer experience involved balancing the three contexts in which the events took place: the inner sense of self, the social environment and medical system with its values and customs where they found themselves as patients. The self is defined as an intrapsychic framework into which new experiences are integrated. The self is both stable and developing and is influenced by social interaction. The two social contexts are the social system and the medical system, both of which interacted with the self and influenced how the experience was perceived and understood by the women. Each of these systems had a greater or lesser influence on each woman's experience depending on how congruent the beliefs, values and practices were with her own perspective and how much power she invested in each one. These contexts continued to interact during the time of treatment and beyond.

Implications for the Clinical Setting

What new patients experience when they first come to the cancer clinic is not only important but may last in their memories for a long time. While those who work with cancer patients are generally aware that the early stages of diagnosis are a sensitive time, the fact that their impact is still felt strongly ten years later may not be sufficiently appreciated. It would appear that from the moment of diagnosis the patients' sensitivity to information and interpersonal relations is substantially heightened by the uncertainty and inherent threat in the situation. In view of the long term impact it is important for clinic staff to recognize the powerful significance of initial contacts with patients in their overall care and treatment.

While the data from this study indicates the diversity and complexity of individual responses to the experience of diagnosis and treatment for cancer, there were some identifiable common concerns. All of the women expressed the need to be treated with respect as valued and capable people. The informants contributed a list of criteria for effective physician/patient communication that fall into two main categories: 1) attitude of physicians and 2) quality of information. The criteria for physician's attitude include such elements as respect, support and genuineness. The criteria for information include detail about procedures, comprehensiveness, adapted to each understanding level and relevant to their concerns about prognosis.

The first meeting with the radiation oncologist was a pivotal experience in regard to the transition from shock and fear to an understanding that they had a treatable illness. They liked her because she treated them with respect, she told them what to expect, and she gave them hope that the cancer was treatable. She directly contributed to their sense of self-esteem. Then, by enhancing their capacity to accurately anticipate the course of events, she also indirectly helped them to restore a sense of control in the face of the cancer challenge. Her confident and respectful attitude contributed to their self-esteem.

An important aspect of the relationship with the physician was receiving information relevant to diagnosis and treatment procedures and outcomes. The women needed to know that they could survive. Through the information they received from the radiation oncologist and her positive attitude, the women were able to regain enough confidence to make sense of their situation. She taught them the language of treatment, so that the least educated of the women could explain in detail what procedures she had gone through.

It is also notable that none of the women said they wanted to make the decisions about treatment, but they did want to know that their doctor was competent, and they did want to know what was going to happen. This points to the fact that gaining information about diagnosis, treatment and prognosis has a direct impact on the patients' ability to make sense of the experience and thus regain a sense of control over the experience, lessening their uncertainty and need for decision making control.

Implications for Counselling

From a counselling point of view, if the counsellor can understand the common concerns of patients, the process of recovery, and those factors that the patients identify as most supportive -- then the counsellor can help the individual patient identify her main concerns as they relate to her self, and can choose the optimal points for intervention and the most effective means to support the patient's return to psychosocial health. Assuming the supporting psychologist is not present at the first clinic visit, this study suggests that those moments ought to be revisited as part of the psychological support process.

Counsellors need to recognize the individuality of patients and the complexity of influences on the ways patients come to understand their experiences. It is important for counsellors to explore the patient's frame of reference, and this can be done by asking the patient about theories they have about how they came to have cancer, how they believe they could survive, and how they see themselves in the experience.

While this study does not lend itself to definitive conclusions about the optimal psychosocial interventions or about what proportion of patients might want or need them, several women did indicate that they might have appreciated talking to someone who was not involved in providing medical treatment or in their social support network outside the clinic. This suggests that at the time of the first referral to the cancer clinic there might be a role for the psychologist in making counselling services available that focus on the impact of cancer on the self-concept of the patient. As that first encounter looms so large ten years later, the research suggest that more could be done to strengthen patient support either through physician education or with counselling.

Finally, for the women in this study, the research interviews appeared to contribute to the on-going process of maintaining their self-concepts through making sense of their experiences. The interviews also helped validate their identification as survivors. Most of the women also indicated that they wished to help others going through the experience of having cancer. The interviews gave them a chance to share their stories in order to help others. One might ask whether it would be possible to build in such opportunities to share their experiences either in follow-up counselling sessions or in a support group of other recovering patients during the extended phase of adaptation after treatment is over. As Fobair and Mages (1981) concluded:

> When patients complete primary treatment and pick up the threads of their lives they may need to continue talking about accepting and understanding the circumstances that now confront them. Communicating about their new perspective on issues such as time, work, relationships, or money may serve to highlight how far they have come since diagnosis (p. 303).

Recommendations for Further Research

One value of grounded theory and other qualitative models is that they provide the tools to go back to the sources and the data and gain more insight into people's behavior and experience. These informants may have yet more to tell. Those who participated in the original study have expressed interest in the research process. Many more questions emerged from the analysis of the data used to explore the original question which motivated this study.

Such questions include: how do the following factors affect the recovery process and the maintaining the sense of self: the physician/patient relationship; disease site; treatment side-effects; various aspects of the hospital culture; personal coping history; pre-existing beliefs and values; a tendency toward introspection; resolution of previous developmental crises; spousal support; maturation and aging? How similar or different are women's and men's sense of self in the recovery process? How does information interact with a sense of control? How do patients judge competency in professionals? The choice of investigative paradigm, of course, would determine whether or not these questions were expressed as formal hypotheses. Numerous studies could emerge from either paradigm.

Additional information could be obtained about the process of maintaining the self from other patient groups. Two specific groups that might be studied would be 1) breast cancer patients because they are women who are dealing with chronic cancer (in contrast to cervical cancer), and 2) testicular cancer patients because they may have similar sexual based issues but, as men, they might have quite different ways of dealing with them.

Male and female differences could be explored further by investigating how men and women appraise their levels of stress and how they utilize social support in maintaining their sense of self. While self-concept is influenced by social interaction for both men and women, men and women may have different criteria for defining the nature of their relationships. The physician/patient relationship might be a focus for gender comparison studies.

Informants from the above groups could be interviewed in a semi-structured format in order to explore the concepts identified in the earlier research and still allow for new data to emerge. From there, a larger study could be developed to test the hypotheses that emerged from these studies. Structured interviews would provide opportunities for informants to give relevant information in their own ways. These could be supplemented with survey instruments such as self-concept inventories and quality of life questionnaires. With standardized instruments, data could be obtained about a larger sample that is representative of cancer patients in general and about which statistical inferences could be made.

Using a quantitative paradigm, the following variables could be developed as hypotheses: changes in self-concept or self-esteem around the time of diagnosis and treatment as compared with self-concept five to ten years post-treatment might be measured using a self-concept scale. Specific hypotheses might focus on changes in some aspects of self-concept but not in others: e.g. that patients would experience changes in their health self-concept but not in their academic self-concept.

The same could be done for quality of life, using a quality of life scale, such as the one developed by Ferrans and Powers (1985), to measure differences between perceived quality of life in specific areas at the time of diagnosis and treatment and five to ten years later. Ideally these measurements would be done with the same sample of patients over time, but also might be done as part of a cross-sectional study.

Researching the question that emerged from the study, "How can effective communication between the physician and patient be strengthened?" would be an interesting challenge in research design. The finding that the moment of diagnosis is so strong even a decade later, and that the patient's attitude towards their own recovery, and their confidence in the physician's competence is greatly influenced by the physician's manner of presentation and the relevance of the information bears greater study.

In summary, this exploratory study has made a contribution by identifying issues that are of concern to some cancer patients and may be relevant to cancer patients in general. For the researcher, the study has increased her awareness of the potential long term impact of the experience of cancer on self-concept and given her the potential to shift the focus of her interactions with patients from problems with cancer to problems with the self. With strengthened clinical support, more women could come away from this experience with this attitude:

> And I probably will live to be a 120. I can be one of those statistics. Actually, that is one of those things that gives me a certain amount of satisfaction. I'm one of those statistics. I'm one of the people who will give some poor soul down the way confidence. And they'll say, "Well this woman had cancer when she was 28, and now she's 72, and she's healthy enough." So some person who is sick then can say "Well look, she lived 50 years; I can do the same."

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Appendix A: LETTER TO POTENTIAL INFORMANTS

Dear

I am doing a research project concerning women who have had cervical cancer. People who have had cancer tell me that the experience affects them over many years. However, we do not know very much about their experience five to ten years after being treated for cancer. I am interviewing women about their lives and their experience of recovering from cancer. I want to invite you to take part in this project.

I am sending this letter in advance to let you know that I will be calling you on the telephone to tell you more about my project and to see if you are interested in participating. I will call you during the week of ----------. If you are willing to participate, then we can arrange a time at your convenience for getting together to talk about your experiences. Anything that you share will be kept confidential. This project has been discussed with your doctor at the [clinic] and he/she has given consent to contact you.

When the project is completed, I will be happy to share the results with you. Also feel free to call me and discuss any aspect of your participation in this project. You can reach me at -------- during the week.

I appreciate your attention and interest in this study.

Sincerely,

Katherine M. Leonard, M.A.
Counselling Psychologist

Appendix B: CONSENT TO PARTICIPATE

THE EXPERIENCE OF QUALITY OF LIFE FOR CERIVICAL CANCER SURVIVORS

CONSENT TO PARTICIPATE: Page One

Principal Investigator:

Katherine Leonard, M.A., Chartered Psychologist,
Counselling and Psychological Services, [clinic].

Faculty Advisor:

Dr. Ronna Jevne, Ph.D., Associate Professor,
Department of Educational Psychology, University of Alberta

Purpose of the Study:

The purpose of this study is to understand the recovery experience of women who have had cervical cancer. Through interviews, participants will be asked to describe specific experiences which have been helpful or unhelpful during the recovery process after treatment for cervical cancer. This study has been discussed with Dr.------ at the [clinic], and he/she has given consent to contact you.

If you agree to participate in the study, you will be interviewed about your experience of recovery. There are no right or wrong answers, and you are not obliged to answer any questions if you do not wish to do so. If the interviews touch upon very deep and personal life experiences, these aspects will be treated with sensitivity and respect. A summary of your responses during the interview will be sent to you for confirmation of the contents.

Confidentiality:

The information that you provide will be kept confidential, under lock and key in Kate Leonard's private office, and only the investigator will have access to the information. When the study is completed you will not be identified by name or in any way associated with the study.

A QUALITY OF LIFE STUDY OF WOMEN WHO HAVE RECOVERED FROM CERIVICAL CANCER

CONSENT TO PARTICIPATE: Page Two

I have read the preceding and this is to certify that I have had the purpose of the above study explained to me.

I understand that I am under no obligation to participate; I may withdraw at any time, or not answer any question without jeopardizing the quality of my care in this clinic.

I understand that the information which I provide will be kept confidential and my identity will not be revealed. The information will be stored under lock and key in the investigator's private office during the study.

I understand that the results of the study may be published, but I will not be identified by name or in any other way, and my name will not be associated with this study.

I have been given the opportunity to ask whatever questions I desired, and all such questions have been answered to my satisfaction. I realize that I can ask for additional information at any time. I will be given the opportunity to see a summary of the final report.

I understand what is required of me and I freely agree to participate in this study.

Participant
Signature:________________________Date:__________________

Investigator:_____________________Witness:_______________

Appendix C: DEMOGRAPHIC DATA SHEET

Study ID#____________________

Please answer the following questions:

Name:____________________________________Age:_________

Address:____

____

Telephone:
(home)___________________(business)__________________

Employment:____

Marital Status: single__ common law__ married__
separated__ divorced__ widowed__

Children:____

[clinic] Registration #:__________________

Health status now (include any hospital admissions, surgeries, or other major illness since your treatment for cancer):

____

____

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Appendix D: SUMMARIES OF INFORMANTS' EXPERIENCES

The following descriptions are synopses of each woman's narrative which highlight the process of her experience. The pseudonyms that they have been given indicate the sequential order of the interviews.

ALICE

Alice, age 38, was diagnosed ten years ago with squamous cell cancer of the cervix, stage IB. She was not married and had no children at the time. Her first abnormal papsmear had shown up two years prior to diagnosis, but the condition of her cervix changed rapidly in the last few months. She remembered her gynecologist being upset by the aggressive progress of the disease. Alice's own attitude was one of "let's treat it and get on with things." She did not feel threatened because she said she always has had "a deep sense that nothing really bad would happen to her."

Alice said that she read about several factors that might have contributed to her developing cancer at that time: 1) her mother had taken medication, possibly diethylstilbestrol (DES), to prevent miscarriage; 2) Alice began taking birth control pills shortly before diagnosis; 3) she experienced increased stress in the two years preceding diagnosis: severe gastroenteritis after traveling to Mexico and a conflicted relationship with a current boy friend. She thought the cancer was probably there and that the stress reduced her ability to fight the disease.

Alice was treated with a total hysterectomy and external beam radiation. She recalled that there was disagreement between the surgeon and the physicians at the cancer clinic about the necessity of radiation therapy as follow up. Alice remembered that it was difficult for her to decide whose advice to follow when she was so weakened by illness. She thought that the married women she saw at the clinic had an advantage of support from their husbands in making decisions.

As a result of radiation she has had chronic diarrhea and severe cystitis due to radiation damage. She had secondary problems of hemorrhaging, anemia and later osteomyelitis. She said that in the beginning physicians denied that she was having the various symptoms, and she was afraid that they saw her as a "troublemaker". Her gynecologist gave her Premarin to reduce symptoms of menopause, but the clinic physicians warned her that hormones could increase the risk of breast cancer.

Her struggle with symptoms over several years limited her ability to function in her work and social life. She received daily support from co-workers who helped her with her tasks, reminded her to rest, and gave her recognition for her ability to cope. In the beginning she worried that each ache or pain might be more cancer. She planned her activities to conserve her energy, anticipating the consequences and balancing what she could do against her need for rest. She had to give up some activities permanently.

Alice remembered those years as a time of frustration and discouragement as there always seemed to be another barrier between herself and her goal of wellness. She felt her sense of self was threatened as everything she knew about herself was changing. She grieved the losses of body parts, fertility, freedom in her sexuality, and the time when she would have done certain activities that she could not do later. She reduced the emotional impact by comparing herself to people who were worse off: who had other kinds of cancer with worse prognosis or who had greater physical handicaps. She struggled with uncertainty about the causes of various symptoms, about long term effects and about her chances for being disease free in the future.

Several years after treatment, as most of her symptoms came under control, Alice's general health began to improve, and she did not need to go to the doctors so often. As Alice gained confidence that her body would perform, she began to feel more in control of the direction of her life. She felt calmer and began "relearning" her life. She saw herself as able to "hold on to many of the things" that were her and simultaneously as "a new you who used to be sick". When she became exhausted she reasoned that it was because she was out of shape not because she was ill. She thought that some of the changes in her self perception were due to maturing rather than due to surviving cancer. She reached a point where she could look back, learn from her experiences and recognize the strengths that had carried her through those experiences.

Looking into the future Alice thought her chances of getting cancer were about the same as anyone else's. On the other hand she felt that she would never lose her sense of vulnerability. She said that "unlike most things, you do not get better at being sick." Although she had no concerns about infertility when she was younger, she now wonders if she faces a lonely old age without children to care for her as she cares for her parents. At the same time she looks forward to continuing her career and considering some alternative paths for her creative expression.

Alice felt that she had lost some quality of life in losing those years when she would have done what she wanted and in continuing to have the problems with diarrhea and cystitis which affect her social life and sexual activity. She rated her quality of life high in terms of her relationships with her family, friends and boy friend. She also felt that she had gained in her ability to adapt to physical limitations and thought that she would be more prepared to handle the physical limitations that come with aging than many of her contemporaries. Her goal is to be a "statistic", as one who has survived cancer and lived into a healthy old age, and thus become an inspiration to others facing cancer.

BETH

Beth, age 35, was diagnosed nine years ago with squamous cell cancer of the cervix, stage IIA. At the time she was single and had no children. She had never been sick before and she remembered the day she heard the diagnosis as the most traumatic day of her life. Never knowing anyone with cancer, she thought she would surely die. That weekend she went to her parents farm, told them and cried a lot. Early the next week she went to the cancer clinic and met the radiation oncologist, who was "the nicest person" she had ever met. This doctor talked to her "like an intelligent human being" and told what she had and what the treatments would be. Beth found that she trusted her doctor completely. She said she did not think about why she had cancer until later when information came out about the female children of mothers who used DES during pregnancy as her mother had.

Beth's next problem was to arrange time off work for treatment. She was reluctant to tell people at work at first but found that her supervisors were supportive even though Beth only had her new position for three months.

They arranged short-term disability, and accommodated her treatment schedule and diminished energy levels. Later the staff became a source of emotional support as they all learned to joke about her treatment. Humor is a major coping strategy for Beth.

Beth remembered her treatments, intracavity and external beam radiation as unpleasant ("yucky") and disrupting her summer that year. She learned to cope with the many tests and examinations by numerous medical personnel by putting her mind somewhere else. The menopausal symptoms such as hot flushes were not debilitating and she was put on hormonal supplements to control them. The main effect that she noticed was that whenever she became over tired in the next few years she felt nauseous. During that time she also tended to attribute physical problems to the cancer or the radiation treatments and sometimes she still wonders what effect "all that radiation" had on her body.

At the time of treatment she was involved in an intimate relationship. Her boy friend was very supportive, but the relationship eventually ended due to causes other than the cancer. She has not found that having had cancer or being infertile has been a barrier to relationships. She always thought she would get married and have children after she established her career. Now she feels that her life is pretty good and she does not regret not having children. She sees herself as a person who has always had a lot of self confidence, who faces life head on and who does not make crises out of things.

Beth noticed that her priorities changed after her experience with cancer. Before that experience her career was the most important focus of her life. Since experiencing the support of her friends during treatment and recovery, she finds she wants more balance in her life between working and the rest of her life. She also projects into the future to assess current decisions: how will she feel at 65 if she does or does not make this choice. Being faced with her own mortality, she wants to take the risks to do things now that will enrich her life. Her decision to take a break from a well established career for graduate studies comes from those decisions about what she values most. Her top criteria for good quality of life are having friends and family and learning something through education and travel experiences. She rates her current quality of life as very high.

CAROL

Carol, age 41, was diagnosed seven years ago with adenocarcinoma of the cervix, stage IB. She was married at the time and had two children, aged 11 and 13. Although she had more childhood illnesses than anyone else in her family, she was still shocked by the diagnosis of cancer.

She said she felt that getting cancer was a matter of being unlucky.

Carol was referred to the cancer clinic where she underwent extensive testing. She said she was glad that they were so thorough about checking rather than waiting until it was too late. She liked the radiation oncologist at the clinic and appreciated her ability to explain everything to people who do not understand "medical lingo". Carol said she needed to trust her doctors and to not worry because worry made things worse.

Carol was treated with intracavitary and external beam radiation. Later, she also had a hysterectomy. Her daily life was disrupted by the treatments and her reactions to them. She had nausea during radiation, followed by diarrhea for two weeks and general weakness after the surgery. She also had gallbladder surgery a few months later. Then for a year or so she experienced menopausal symptoms such as irritability, moodiness and loss of interest in sexual activity - causing stress in her marital relationship. The doctor gave her a hormonal supplement and Carol noticed a big difference in her general attitude and in her enjoyment of sexual activity.

The support of her husband and children helped her through the first two years after treatment. Carol felt eassured that they considered her important and did not ant to lose her. She said they are still very protective of her. She also felt that her ability to talk things over with her husband helped her to recover. She contrasted her experience with women who saw cancer as shameful and could not talk to anyone even those close to them. "If you don't have support from your family, you're kind of lost".

Carol said that her priorities have not changed since cancer. To have good quality of life, she needs to be able to live, relax with her family, have a safe home, and give love to everyone in her family.

DORIS

Doris, age 48, was diagnosed eight years ago with adeno-squamous cell cancer of the cervix, stage IIB. She was widowed and had four children, aged 12 to 19. When she was told that she had cancer, she thought that would be the end of her and began to prepare for "termination of everything". Doris described herself as a person who did not communicate well with her peers and expected their responses to her situation would have been negative. Consequently she resigned her position without explanation and never told anyone where she worked about her cancer diagnosis. However, she said her experience changed when she was referred to the clinic and met the radiation oncologist. Doris said that the doctor's positive attitude and factual information gave her feelings of empowerment and hope. She contrasted her experience with doctors who coerce their patients with threats of death if they do not follow the doctor's wishes. Doris read several books and articles on how attitude could make a difference in fighting the disease and thought her negative attitude had contributed to her developing the disease. After her husband's death she had experienced extended grieving and felt that she had lost control of her adolescent children to the point of no longer caring whether she lived or not.

Doris was treated with external beam and intracavity radiation. She took a year off from working to regain her strength. She has not been sexually active since her husband's death, so she experienced no change in sexual functioning. She did not take hormone supplements long after the treatment because she was afraid of the increased risk of cancer. She felt that adhesions in her vaginal canal made the annual pap smear more difficult and wondered how she would know if the cancer recurred. She also wondered whether the radiation had reduced her stamina and caused her body to age more quickly.

During treatment and after, Doris turned to her strong religious beliefs for support. As a single person she said that she did not receive much support from the church community. After her husband's death she had many questions about the meaning of life that set her apart from the women her own age. When she was diagnosed with cancer she thought that people with a little medical knowledge would label her as promiscuous though that was not the case. She mainly looked for answers in books and television information programs and developed her own theories. Doris felt it was important for her to hold to her own values in a world where standards are changing so fast.

Since her treatment, Doris tries to maintain a positive attitude. She decided that she had to live for herself and not get involved with other people "to the point where you don't want to live because other people's lives are messed up". Doris admires the pioneer women who had to face many hardships and losses and still managed to begin again. She said that she does not allow herself to be overwhelmed by problems because she thinks that might trigger relapse. However she does feel that she has to push herself at work and that she does not stand up for her self very well and that she still tends to put others' needs before her own. She said she is still learning what areas of her life she can control and what areas are beyond her control.

In order to have a good quality of life, Doris said her primary need is for "spiritual food", followed closely by good family relations which she currently has. She would like to learn to communicate better with people and be able to share her ideas with them.

ELLEN

Ellen, age 54, was diagnosed nine years ago with squamous cell cancer of the cervix, stage IB. At the time she was in a common law relationship and had several children from a previous marriage and the current relationship, aged 8 to 27. When she was 40, her family doctor suggested that she have regular pap smears. She was conscientious about semiannual tests because her aunt had died of cervical cancer when Ellen was 9. Then one of the tests showed abnormal cells, and she was sent to a specialist who did a biopsy and from him to the cancer clinic. Her first thoughts upon hearing the diagnosis were of her aunt and how she had died at a time when cancer was found too late. She met the radiation oncologist at the clinic and really liked her because "she really explained everything well". It is evident that Ellen obtained the information she needed: even now she has detailed knowledge of the tests that she went through and medical nomenclature used in the clinical setting. She developed an idea that the cancer was passed to her from her common law mate whose first wife died of cervical cancer. She never checked her theory with her doctors. Because of her understanding of the nature of her situation, Ellen said she was not afraid nor bothered about going through the treatments.

Ellen had intracavity and external beam radiation. She described an incident during one insertion when the doctors took her back to the operating room to correct a misplacement detected by the x-ray. Her confidence in the doctors was affirmed by the care they took rather than shaken by the mistake. The major physical change she experienced was menopause. She decided to forgo hormonal supplements because she did not want to become dependent on medication. She said the symptoms lasted about two years. She said that sexual activity gradually ceased over the years, perhaps due to the unsatisfactory nature of her spousal relationship. Her spouse was not a source of support during her treatment and recovery.

Ellen's main source of support came from her children. They looked after themselves and their home with minimal direction from her. She did not need the support offered by her many younger brothers and sisters, but they kept in contact and wanted to know everything about her experience. Ellen's women friends are also younger and look to her for information about her experience. Ellen said she has strongly advised her daughters, sisters and friends to have regular papsmears. She believes that she survived because of the cancer being found so quickly.

Ellen still has annual check ups at the clinic. She said she probably would not be scared if she has a recurrence because if she was going to be scared at all it would have been the first time. She has had good care from doctors in the past and believes that she would be in good hands in the future.

Ellen said that she needs time to rest and be comfortable in order to have good quality of life. Now that she is separated from her spouse, at least temporarily, she can enjoy visits from her adult children and she can go out for Bingo whenever she likes.

FREYA

Freya, age 58, was diagnosed ten years ago with adenocarcinoma of the cervix, stage IB. She was married at the time and had two adopted children, aged 15 and 17. There was a delay in diagnosis of more than 6 months although she knew there was something wrong. She wondered what would have happened if they caught the cancer earlier. When she was told the diagnosis, she was devastated but was glad to be referred to the cancer clinic rather than somewhere else. She thought the radiation oncologist was terrific because "she explained everything to a T: you knew about your body and what was happening and what they were going to do". Her husband was included in the medical discussions so he also understood. She said it was important to know the risks so that they could go from there.

Because she had many vaginal infections she always thought that if she got sick it would be in her female organs. If there was a purpose in getting sick, Freya thought it might be to make her more aware of her own needs and begin to look after herself more carefully.

For treatment, Freya had two intracavity insertions, external beam radiation and a hysterectomy. She tolerated the treatments well and discovered her inner strength. She said she could be strong for her chronically ill husband because if she died there would be no one to care for her husband and her children. Though she had not been able to have children and had reached menopause, she said it was a shock to lose her uterus. The radiation treatments altered the tissue of her vagina so that even ten years later she feels a burning sensation during intercourse. However the strength of her marital relationship has withstood the physical changes. Freya said the discussions with the clinic physicians were helpful in encouraging them to continue their sexual activity.

Freya was glad when she was told that she did not have to go back to the clinic. She generally does not think about cancer unless something reminds her. She read that women who have not had children are at higher risk for breast cancer; and since she had cancer once, she knows she is not immune to the possibility of getting another kind of cancer. If she did have a recurrence she thinks she would handle it the same as the first time: put her faith in the doctors and fight to the best of her ability to get well.

While she was growing up she experienced the deaths of both of her parents and a baby brother and later the deaths of two sisters. Those experiences and her own illness taught her that time is precious. "You're aware of so many things. It seems as if you wake up and you see things more clearly...even the sun coming up." She said she has a generally positive attitude and her quality of life is good because she has the love and caring of her family and the opportunities to take care of them and help others who are less fortunate.

GAIL

Gail, age 39, was diagnosed eight years ago with stage IB squamous cell cancer. She was married at the time and had three children, ages 8 to 13. Gail said that she had not gone to a doctor for seven years before she began to show symptoms: bleeding and dysparunia. The diagnosis was scary because of what it might mean. However the doctor at the cancer clinic was "wonderful" because she explained everything and reassured Gail. During treatment Gail was supported by her husband who took time of work. She told her mother and siblings and had to contend with their various reactions. She said she had no theories about how she got cancer: it could have happened to anyone.

After the acute effects of treatment, radiation burns, Gail had a long term struggle with chronic diarrhea. She has now reached a point of frustration with increasing impairment and is pursuing further assessment and possible treatment. Like the others, she went into menopause and had a synthetic estrogen prescribed. As a result she was hospitalized three times with blood clots in her lungs and no longer takes estrogen. Those experiences were more frightening to her than the diagnosis and treatment. Another major long term effect for her was the decrease in frequency and pleasure in sexual activity. Recovering physically has been an ongoing struggle.

However, the most important change that Gail wanted to tell me about was the significant improvement in her relationship with her husband. Perhaps because he realized that he could lose her, he began to stay home more and they talked together more. He also became more involved in parenting. Now they have a business together and spend most of their leisure together as well. She finds that talking about her experience is helpful. Nevertheless, she has learned to be more discrete since a business rival tried to use her cancer experience to beat them out of a contract, saying that she could not handle the job.

She often thought she survived because she has a very positive attitude and believes that what will be will be. She saw it as a real experience that changed her life. She said she learned to take one day at a time and not worry about the future. Her main concerns had been for her children and they had all turned out fine.

Although she no longer goes to the cancer clinic, she does not feel she has recovered, given her chronic diarrhea. Her chronic symptoms make it difficult for her to interpret signs of ordinary illness. She still feels reluctant about going to the doctor but does so regularly because of her family's insistence. She thought that if she has a recurrence, it would be scary because the doctors had not cured her cancer. Her quality of life criteria focussed on the health and happiness of her family. In talking about someone who committed suicide, she said "nothing can be really that bad that you have to give up your life."

HAZEL

Hazel, age 52, was diagnosed ten years ago with stage IB squamous cell cancer. She was married at the time and had four children, aged 13 to 22. Her gynecologist noted that she had an abnormal papsmear but did not follow up. Six months later she changed gynecologists. The new one put her in hospital for a biopsy right away. When she heard cancer, she thought she would die. For her generation cancer was a "dirty word" that meant at least social isolation, so she did not tell anyone except her husband in the beginning, and they cried together. She told her one brother three years later and never did tell her mother.

However her experience changed when she went to the cancer clinic. She said the radiation oncologist was excellent: she put Hazel's mind at rest and treated her as important. All the staff at the clinic were better than in other hospitals she had known: "hand picked". A porter helped her through pre operation anxiety and another patient helped her during her first hospital stay.

Hazel thought at first that she must have picked up cancer from toilet seats and later that we all have cancer in us all the time waiting to be triggered off. She did not check out her theories with her doctors.

The treatments were not as bad as she expected and when she survived the last implant she knew she was going to live. The impact on her family and the need of her children helped her firm her resolve to live. She thinks her early experiences with her brother as "war children" helped her value family closeness in survival. She also compared herself with other patients at the clinic and felt she was better off and certainly not a pariah. She read everything she could on cancer. The most difficult part was facing the end of childbearing because she felt she was most valuable as a mother.

Hazel said she was not religious but prayed a lot and that and her need to be there to guide her children may have kept her alive. She feels lucky to be alive, but the thought of cancer is always at the back of her mind and she does not know what might trigger it again. She has regular check ups but feels apprehensive each time. She does not know how she would handle a recurrence because she believes that it would more likely mean death than the first time. She would try to be positive and fight again.

Hazel considers her quality of life good because she and her family have health. She feels she has learned to appreciate the simple things in life and the importance of putting more care into the things she does. She wants to educate herself and find ways to contribute to the welfare of others.

JEAN

Jean, age 45, was diagnosed eight years ago with adenocarcinoma of the cervix, stage IB. She was married and had one daughter, age 18. Although Jean did not talk about her reaction to the diagnosis, her many statement about her strong religious faith would suggest that her faith and her determination to carry on sustained her through the initial shock.

Jean said that the radiation oncologist at the clinic was excellent and very competent: she was very thorough and didn't leave anything to the imagination. For Jean it helped that they were both professionals.

She had good strong family support at the time. She did not need to talk to anybody outside her family who might bring in negative things about cancer. She chose not to trouble others, including her mother whom she did not tell until it was almost over.

She did not tell any of the people at work and treated her appointments at the clinic like any other appointments that her staff booked for her. It was important for her to continue to be involved in her normal activities. She had to be in hospital for surgery but it was not necessary to explain to colleagues: women of her age often have hysterectomies.

No one in her family had had cervical cancer. She knew that the type of cervical cancer she had was unlikely to be passed venereally. She supposed that there was a reason for her to have had this experience but did not know why. She believes the Lord gave us our bodies and also provides the repairs.

She did not have any trouble with the treatments. The worst part was all the testing in the beginning. She felt her understanding of the technologies used in testing and treatments helped her contend with the fear and confusion other women might have experienced. She had the radiation treatments and then a hysterectomy six weeks later. She has had no side effects from treatment. She has not had any symptoms of menopause since right after the surgery. She does not take hormonal supplements other than Premarin cream which works fine. She just dealt with the situation and carried on. She would rather not dwell on past experiences. Once the treatment process was over, she closed the door and she never looked back.

She does not worry about cancer. The doctors say that since she had cancer they have to be very careful. She had a biopsy of a breast lump, but she knew it would be okay and it was. She understood why the doctors were careful and was pleased with the quality of doctors at the clinic. Later her daughter showed some abnormal cells on her cervix and was successfully treated at the same clinic. Jean is very close to her daughter.

Jean believes that she is a fortunate person and that she is not any different than she was before the cancer: she was happy then and she is happy now. She loves what she is doing and loves to experience new things and meet new people.

Her criteria for good quality of life include a healthy attitude, being positive, good nutrition, and enjoying "the things that are here for us [but] not in excess however, in terms of food, etc.". Being more thankful to God for his ever present love and guidance.

She would like to find a way to contribute to others going through the experience of cancer, perhaps on one on one basis someday. She believes these opportunities will present themselves when she is ready.

KAREN

Karen, age 52, was diagnosed 9 years ago with squamous cell cancer of the cervix, stage IB. She was married at the time and had two children aged 14 and 18. Although she had regular check ups her family doctor did not follow up on her abnormal papsmear until 3 or 4 months later when she began to have symptoms of bleeding. She wonders if she might have had a more mild treatment if her doctor had responded sooner. She remembers that the diagnosis of cancer was a shock and that she thought at first that she was going to die. She has a strong religious faith and was not so much afraid of dying as she was sad about leaving her family behind. Her family and members of her church provided a great deal of support during the initial crisis. They were more important to her than her relationship with the doctors at the clinic. However she said it was very reassuring to her that the doctors made a thorough evaluation of her disease and brought together so much knowledge and technology for her benefit.

She thought that she might have gotten cancer because her father had cancer or she might have been an isolated case. Her father died of cancer at the same age she was when she was diagnosed.

Her religious faith gave her the peace of mind to cope with the intracavity radiation. She found external beam radiation more difficult to tolerate because of vomiting and tiredness. She thought she would have quit if there was even one more treatment. She found that afterward she could never eat as much as she did before and yet her stomach remained distended and hard. The doctor put her on hormone supplements right away so that she did not experience the symptoms of menopause. She was expecting menopause and did not want any more children so that infertility was not a problem. However the pain she experienced in intercourse after treatment, while decreasing over the years, has led to a decrease in sexual activity even to the present.

She returned to work gradually after 5 months. She had no trouble with telling workmates about her cancer if they asked. She found her supervisors helpful in modifying her job until she regained her strength. She felt that her own family was brought closer together because of the experience.

She believes that she was healed by God. She does not worry about recurrence. She believes that she would be more knowledgeable about cancer if she had it again. She found the annual clinic visits reassuring and was sad when she was told, after 7 years, she did not have to come back to the clinic any more but could be followed by her doctor.

Her quality of life criteria focus on the welfare of her children, her husband and herself. Realizing that she might have limited time, she has become conscious of doing the things she needs to do now: from having her life spiritually in order to enjoying travelling to learn about her roots and people of other cultures.