

THE MEANING OF CANCER IN A NEW MARRIAGE

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ABSTRACT

This study explores the meaning of cancer as experienced by newly married couples. The participants were engaged as co-researchers in an attempt to understand this unique experience. In the initial interview, questions were asked to encourage storytelling and introspection. The goal of the collaboration was mutually understood to be the creation of stories that would accurately reflect each couple's experience and illuminate the meaning of that experience. Narrative accounts from the initial interviews were examined and validated by each couple in a second interview.

Each narrative account was then rigorously analyzed to find themes of meaning, which were compared across accounts. Important themes emerged, giving new insights into the processes of deconstruction and reconstruction that helped the subjects to survive and make sense of the cancer experience.

This study contributes to the body of research on the subjectively lived experience of cancer, and in important ways challenges some of the assumptions in the oncology literature. It is clear from the narrative accounts, for example, that the concept of recovery as an individual, sequential, and finite process does not accurately describe the recovery processes of these subjects, who experienced recovery as an ongoing, lifelong process occurring within a variety of individual and interpersonal contexts.

TABLE OF CONTENTS

ABSTRACT	ii
TABLE OF CONTENTS	iii
ACKNOWLEDGEMENTS	iv
DEDICATION	v
CHAPTER I: INTRODUCTION	1
CHAPTER II: REVIEW OF THE LITERATURE	5
CHAPTER III: METHODOLOGY	35
CHAPTER IV: NARRATIVE ONE: BRAD AND ELLEN	50
CHAPTER V: NARRATIVE TWO: GERRY AND LINDA	60
CHAPTER VI: NARRATIVE THREE: NED AND TERRI	71
CHAPTER VII: NARRATIVE FOUR: ROB AND SUSAN	83
CHAPTER VIII: NARRATIVE ANALYSIS	92
CHAPTER IX: DISCUSSION	113
REFERENCES	127
APPENDIX A: RECRUITMENT NOTICE	150
APPENDIX B: PARTICIPANT CONSENT FORM	151
APPENDIX C: INTERVIEW PROTOCOL	152
APPENDIX D: SAMPLE TRANSCRIPT	153

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DEDICATION

This study is dedicated to four very special people:

To my parents, who are both cancer survivors, with gratitude for their love, laughter, and support.

To Gerald, whose beautiful smiling self was taken from us much too soon by testicular cancer, but whose spirit lives on joyously in my heart.

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CHAPTER I

Introduction

Cancer as a word and as a metaphor has many meanings, and each individual cancer journey reveals a distinct landscape of meanings. When cancer occurs in the context of a new marriage between two young adults who are just starting out in life, the experience will ultimately depend on how these meanings impact their particular journey.

In Canada in the year 2001, there will be an estimated 6,350 new cases of cancer diagnosed among young adults aged 20 to 50 years of age, and an estimated 1070 deaths. The totals are approximately the same for men and women in the 20 to 29 age group, but considerably higher for women in the 30 to 39 age group. Incidence rates for cancer in this age group have remained stable through 1971-2001, with mortality rates showing a moderate decline. Males in the 30 to 49 age group have the highest probability of dying from lymphoma, melanoma, or colorectal cancer, while for females the highest probability is for lymphoma, melanoma, or breast, cervical, or ovarian cancer (all Health Canada, 2001).

While it is true that the experience of cancer can be one of life's most difficult, accompanied by physical pain and disfigurement, emotional turmoil, spiritual reevaluation, social isolation, personality changes, career obstacles, financial hardship, and loss of sexual and reproductive functioning, it is also true that from the threat of destruction inherent in the experience can come transcendence and self-transformation. As the neoplastic cancer cells appear unbidden in the body, so too can previously unknown and untapped energies and capabilities appear. As Dreifuss-Kattan (1990) says, "a unique dialectic emerges between illness and health, between despair and new hope" (p. 3). It is a presumption of this study that for young, newly-married adults, this dialectic, embedded as it is in experience and meaning, must be different and unique.

It is another presumption of this study that the cancer experience can be said to occur in

three broad contexts. The first is the sociocultural context, in which social attitudes and cultural beliefs about cancer form the environment in which the experience will occur. The second is the medical context, which refers to such considerations as stage, treatment type, and cancer site. The third is the psychological context, which considers each individual's mental and emotional capabilities and constructs as they relate to the experience. This study is concerned primarily with the third context, although it is evident in the research that the cancer experience occurs simultaneously within all three contexts.

The fact that the cancer experience of young, newly married couples, including the psychological impact of that experience and the adjustment processes required for its successful negotiation, has not been explored in depth indicates a gap in counselling theory and practice. Narrative accounts such as those in this study can contribute to the type of in-depth understanding of lived experience that can support new theories, counselling strategies, and program design and implementation.

Purpose of the Study

What is the meaning of cancer for newly married young couples? This study will attempt to provide some answers to that question. Certainly the individual experience of cancer and the impact of cancer on spouses and families have been studied, but there has been very little research on the impact of cancer on young couples who are in the early years of their marriage. The meaning of a cancer diagnosis for such couples, coming at a time when they are just beginning to establish roles and identities within the marriage, work out issues around family, career, and children, and plan for the future, has not been studied or understood. For many of these couples the cancer experience represents an extremely traumatic and dissonant event which irrevocably alters their lives and changes the character of their marriage. This study will try to understand what the cancer experience means to young, newly-married couples.

Rationale

The literature on counselling spouses with cancer generally presumes a mature, well-established marriage. Cancer experienced by young, newly-married couples is a different and unique phenomenon and needs to be investigated.

Following from the above, it is imperative to understand the meanings that young married adults employ in thinking about cancer, as these meanings can have a profound affect on the experience and outcome of the individual and shared cancer experience.

Most available research on cancer looks at impact rather than meaning. By illuminating the meanings ascribed to cancer, a deeper understanding is achieved, one which attends to important factors such as age, gender, body image, culture, and family history.

Present generations are more likely to turn to counselling for help than previous generations. To meet this need, counsellors need to be familiar with the particular issues that young couples facing a life-threatening illness would bring to counselling.

Marital instability decreases the chances of successfully adjusting to the cancer experience. Research that sheds light on how spouses nourish and reinforce the marital bond during the cancer experience can contribute to counselling theory and practice on marital adjustment to crisis and change.

More and more, the holistic approach to health is showing that cancer and other illnesses need to be treated along the entire mind-body-spirit continuum. By showing how cancer is subjectively experienced by young couples, this research study will contribute to the growing rapprochement between traditional medicine and the humanistic disciplines.

Research Design

To elicit meaningful case study data, the semi-structured research interview format is chosen so that the participants have the opportunity to tell their stories in sufficient depth and detail. Counselling skills such as active listening, empathy, immediacy, clarifying, and paraphrasing create

an environment of respect, trust, and understanding in which meaningful stories can be told. The interviews produce qualitative research data in the form of transcriptions from the interview tapes. These transcriptions are condensed into narratives which represent as accurately and completely as possible the stories told by the participants. Each narrative is analyzed using techniques of narrative analysis and presented as a narrative case study, which is verified by the participants. The researcher compares narratives in order to develop themes, and tests the validity of the thematic analysis through independent external review.

The above attention to methodological rigor ensures that the research has the highest possible degree of trustworthiness. In addition, the researcher's counselling and volunteer experience at the BC Cancer Clinic and the BC Cancer Society provides insight, familiarity, and understanding throughout the research process.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

It is only in the last 20 years that there has been a concerted effort to understand the psychological effects of cancer. The new discipline of psychooncology has emerged in response to a growing awareness of the importance of theoretical understanding and therapeutic guidance. An expanding repertoire of research methodologies is being used to study the impact of cancer from a perspective that values personal and contextual domains of epistemology. One research phenomenon which has not been adequately studied, either in theory or in practice, is the impact of cancer on young adults, either individually or within a relationship. Researchers have commented on both the lack of empirical research data on this subject and the corresponding lack of clinical intervention work (Germino et al, 1995; Northouse et al, 1998; Rolland, 1994b).

This chapter reviews the literature on cancer and marriage as represented in the most relevant areas of study, with particular attention paid to sources that provide information on young couples between the ages of 18 and 40. Since this research is based on the assumption that meaning is the central organizing concept of human experience, the following review views each area of study through the lens of meaning.

The Biomedical Approach

Based on molecular biology, the biomedical model assumes that all disease can be understood in terms of deviations from measurable norms. Researchers working within this paradigm have concentrated their efforts on quantitative studies that measure the correlations between marriage and cancer incidence, survival, recurrence, and mortality. Given the diversity of measures used and the limited amount of data available, it has not been possible as of yet to draw any firm conclusions about these correlations (Holland, 1998).

Although the biomedical paradigm has lost the absolute power and authority it once had, we

shall see throughout this review that it continues to be a pervasive influence.

The Biopsychosocial Approach

In response to sociocultural trends, increased patient awareness, and influential advocacy in the field (Engel, 1977; Kimball, 1981; Reiser & Rosen, 1984; Silverman et al, 1983), there has been a steady shift away from the unidimensional, nosological approach of the biomedical model towards a more holistic, person-centred understanding of disease. This new approach, or biopsychosocial model, is premised on the belief that disease can only be understood by considering not just the biomedical indicators but also the individual's psychological and sociocultural influences, which are seen to have a crucial effect on the course and outcome of the illness.

In early studies on the impact of cancer, biopsychosocial researchers tended to focus exclusively on the affected person or "patient", and any effects on the patient's spouse were largely ignored. One of the first studies that did investigate the non-affected spouse (Klein et al, 1967), although not limited to cancer patients, revealed spousal levels of tension and somatic symptoms that were equal to or greater than that of the affected spouse. In the 1970s several researchers (Grandstaff, 1976; Klein, 1971; Wellisch et al, 1978; Witkins, 1979) confirmed these findings, and in so doing joined the growing contingent of professionals who thought it important to conceptualize disease as an interpersonal phenomenon.

It was not until the 1980s, however, that researchers began to pay serious attention to the impact of cancer on spouses and other caregivers. Most of these studies focused on the assessment of spousal adjustment to distress, thus showing the continuing influence of the medical community's emphasis on the pathology of illness. In an influential study by the preeminent researchers in the field (Baider & Kaplan De-Nour, 1984), small samples of post-mastectomy breast cancer survivors and their husbands were assessed using psychometric instruments to measure their levels of psychological distress. The researchers' findings corroborated early studies by showing that the psychological distress and adjustment difficulties of the husband, as measured by the Brief

Symptom Inventory, were as serious and debilitating, and in many cases even more so, as those of their wives.

In the 1980s and 1990s, a large body of research work definitively established that non-affected spouses experience as much or more psychological distress as affected spouses (Baider et al, 1996; Cassileth et al, 1985; Keitel et al, 1990; Keller et al, 1996; Northouse & Swain, 1987; Oberst & James, 1985). It was also found that some spouses may try to offset their partner's distress by a compensating lack of projected distress (Lee Walker, 1997), and that spouses may underestimate their partner's distress and the value of spousal support in coping with it (Dar, 1992). Although significant correlations have been found between spousal impact types and levels (Baider et al, 1996), it is still unclear whether there is any causal relationship.

In studying psychological distress levels, most studies have investigated the immediate or post-treatment effect on spouses. Of the few studies that have studied the longitudinal effect, conflicting results have been obtained. Ell et al (1988) showed an overall increase in distress over time, Kaye & Gracely (1995) found that certain types of distress can increase over time, Hoskins (1995) reported a decrease in distress in both spouses, and Northouse et al (1998) reported decreases in marital and family functioning, more uncertainty, and more adjustment problems. The latest longitudinal study, also conducted by Northouse et al (2000), found significantly higher levels of distress and less social support in spouses than in patients, but also decreases in emotional distress for both spouses over time.

Several studies have posed the question of whether and how one spouse's distress affects the other. It has become clear that spousal distress has a reciprocal effect, with each individual spouse's distress type and level contributing to the distress of the other (Baider & Kaplan De-Nour, 2000; Kaye & Gracely, 1993). Spousal distress has also been shown to be influenced by the type and level of perceived support from family and friends (Ptacek et al, 1997; Manne et al, 1997).

Gender has also been investigated as a mediator of the distress experienced by cancer patients' spouses (Baider et al, 1989; Hart, 1986; Murray & McMillan, 1993). In a recent study,

women reported more distress, more role problems, and less marital satisfaction regardless of whether they were the cancer patient or spouse (Northouse et al, 2000). As conflicting results have been obtained overall, however, no conclusions on this topic have as yet been drawn.

With the increasing acceptance of counselling as an important tool in cancer intervention, many studies have attempted to identify the factors that affect psychological distress and adjustment in spouses (Carter & Carter, 1993; Ell et al, 1988; Hannum et al, 1991; Hoskins, 1995; Keitel et al, 1990; Northouse et al, 1998; Pistrang & Barker, 1995). Perhaps the most significant finding from such studies has been Hannum et al's (1991) reporting that interpersonal variables in husband-wife relationships were equally as important or more important than individual variables in the effectiveness of coping with cancer.

Other studies with a therapeutic focus have attempted to determine the most prominent concerns of the spouses of cancer patients (Gotay, 1984; Laizner et al, 1993; Northouse & Peters-Golden, 1993; Oberst & James, 1985; Zahlis & Shands, 1991). Among the major concerns revealed by these studies were dealing with fear and the possibility of a negative outcome (e.g. disfigurement, divorce, sterility, death), helping the affected spouse cope with the emotional effects of the cancer, managing the changes and disruptions in daily life resulting from the disease, negotiating communication about the disease with the affected spouse, adapting to shifts in dependency and role identity, and coping with anxiety about future child-bearing capabilities.

In identifying the spousal concerns discussed above, some researchers have taken the inquiry a step further and classified common concerns or stressors according to a unifying theme. Lewis et al (1985), for example, identified powerlessness, ambivalence, role restructuring, interdependence, uncertainty, and the need for resiliency as concepts that characterized all phases of the spousal cancer experience.

Many studies have assessed the reactive processes and coping strategies that spouses employ, both as a team and as individuals, in order to negotiate the cancer experience (Baider & Kaplan De-Nour, 1988; Dunkel-Schetter et al, 1992; Ell et al, 1988; Hannum et al, 1991; Lichtman

et al, 1987; Ptacek et al, 1994). Not surprisingly, the majority of these studies have found significant correlations between spousal style and degree of coping, outcome, and marital satisfaction. Ptacek et al (1994), for example, found that the coping style and effectiveness of one spouse correlated with the mental health and marital satisfaction of the other spouse.

Although the role of support in spousal adjustment to cancer is a relatively new focus of investigation, it has been established as an area of crucial importance. For the married individual with cancer, it is the spouse who shares most intimately the ongoing process of cancer diagnosis, treatment, and recovery, and the spouse who tends to be the main caregiver in both emotional and practical terms (Barraclough, 1999; Cutrona, 1996; Goldberg & Tull, 1983). A spouse's attitude and behaviour during this time can be, and usually is, a crucial element in how the cancer will be dealt with in the moment and how it will be ultimately incorporated into the couple's marital history. Noting that a spouse is sometimes iatrogenically displaced by a well-meaning professional, Goldberg & Tull (1983) identified five key contributions that the spouse can make: help maintain social support, promote the patient's sense of autonomy, be an advocate for the patient when necessary, encourage communication with family and friends, and facilitate the expression of emotion.

It has been well established by researchers that there is a significant relationship between spousal interactions and adjustment to cancer (Baider & Kaplan De-Nour, 1984; Cassileth et al, 1985; Northouse & Swain, 1987; Oberst & Scott, 1988; Omne-Ponten et al, 1995). Feeling supported by a spouse has been shown to be one of the most significant factors in helping marital partners cope with the cancer experience (Hoskins et al, 1996; Lee Walker, 1997); in one study (Neuling & Winefield, 1988), the spouse/partner was nominated by over 90% of subjects as the most supportive family member. It has even been shown that the way a spouse copes with the cancer experience can determine the other spouse's level of adjustment better than that spouse's own coping behaviours (Hannum et al, 1991). The salutary effect of spousal support has been attributed to a positive correlation between effective caregiving and immune function (Baron & Cutrona,

1990).

Given the above, it is not surprising that researchers have found a correlation between marital status and quality and psychological adjustment to cancer (Burman & Margolin, 1992, Fuller & Swensen, 1992; Hannum et al, 1991; Weihs et al, 1999). In a recent study of this phenomenon that employed the Marital Adjustment Scale and two other measures, Rodrigue & Park (1996) found that unmarried adults reported more adjustment difficulties than married adults, and that patients with high marital quality reported less depression and family problems and a more positive health care orientation than patients with low marital quality. Theoretical explanations for the results in these studies have been linked to either the main-effects model of adjustment, in which support is seen to enhance adaptation regardless of stress, or the stress-buffering model, in which stress is mediated by positive support (Rodrigue & Park, 1996).

As is evident in the body of research work cited above, the biopsychosocial approach to questions about cancer and marriage continues to share with the biomedical approach a preoccupation with assessment, quantification, and deviation from prescribed norms. The solidly forged connection between physiology and behaviour remains strong, as in such reductionist views as Moynihan's (1991) observation that "the influence of cancer on relationships appears to be related to histological differences" (p. 245). Most research data is obtained through the use of assessment instruments such as the Brief Symptom Inventory, the Mental Attitude to Cancer Scale, the Cancer Behavior Inventory, the Dyadic Adjustment Scale, and the Psychological Adjustment to Illness Scale. Perhaps the most widely used measure has been the Karnofsky Scale, which assesses physical activity as an indication of quality of life. Some research efforts have attempted to bridge the gap between quantitative assessment and qualitative understanding, such as Domino et al's (1991) Cancer Metaphors Test and Pistrang et al's (1997) case-driven analysis of help-intended marital conversation.

In summing up the biopsychosocial approach, it can be seen that the majority of work so far has rested upon the assumption that the primary attribute of the cancer experience is distress. It

also remains true that only a small amount of the biopsychosocial research on cancer is devoted to married couples, and none to young, newly-married couples. At the end of the millennium, a comprehensive review of cancer in the marital context (Manne, 1998) found that research in the field had become more wide-ranging, but the main concentration was still on breast cancer. Although certainly such studies yield valuable information with some degree of generalizability, it seems clear that the topic of cancer and its impact on marriage has not been adequately studied.

Psychooncology

Psychooncology, also called psychosocial oncology, can be defined as the study of "the psychological, social, and behavioral dimensions of cancer from two perspectives: the psychological responses of patients at all stages of the disease and their families...and the psychological, social, and behavioral issues that influence morbidity and mortality" (Holland, 1998, p. 3). Although the profound psychological impact of cancer has been well known for many years, research and intervention have not kept up with medical advances. It has been said that "the most immediately important task of psychooncology is to close the yawning gap between current knowledge and actual clinical care of patients" (Greer, 1994, p. 102).

The first studies of psychological adaptation to cancer were conducted in the 1950s (Abrams & Finesinger, 1953; Shands et al, 1951). Much of the subsequent research with cancer patients focused on the etiological question, attempting to establish a link between personality and morbidity. A significant study in the 1960s (Oken, 1961) questioned the fact that more than 90% of doctors did not tell their patients that they had cancer. In the 1970s, psychiatrists established an influential presence in oncology units, providing expert counsel on patient, family, and staff psychological problems. At this time the work of Kübler-Ross (1970) with dying cancer patients brought a new awareness to thanatological issues in the cancer setting.

In the 1980s, as epidemiologists became aware of links between cancer and behaviours such as smoking, alcohol abuse, and overexposure to sun, the focus turned to psychological issues

related to prevention, early detection, and compliance with treatment. National cancer organizations began to support psychosocial research, and the new discipline of psychoneuroimmunology undertook an exploration of the relationship between psychology, the immune system, and cancer risk.

Psychooncology as a discipline is still heavily influenced by the medical model. Clinical issues, especially diagnosis and symptomatology, continue to be the focus, with the cancer-affected person's caregivers seen as "second-order patients" (Holland, 1998). The family cancer experience is approached from the standpoint of "medical crises", "poor performance of supportive care", "conflict and/or communication difficulties", and "psychiatric symptomatology" (Holland, 1998). Psychosocial issues are seen not from the cancer-affected person's viewpoint but from within externalizing categories such as "pain", "diagnosis", and "terminal illness" (Guex, 1989). Adjustment to cancer is discussed within the context of "the prevalence of psychiatric diagnoses as a measure of psychological well-being" (Tope et al, 1993).

Although the importance of the marital relationship to the cancer-affected person's well-being is well documented, most psychooncology texts are cursory at best in discussing this subject. Guex (1989), for example, states that "the role of families, partners, and friends is fundamental", but claims that research shows that "the most important person is still always the doctor" (p. 105). Holland & Rowland (1989), while acknowledging that spouses are "deeply involved and live through the patient's experience vicariously with great intensity" (p. 588), devote more space to parents, children, and siblings of cancer patients. Barraclough (1999) includes a seven-page section on "Partners", but restricts her coverage of the subject to such practical matters as communication barriers, sexual problems, and help for caregivers.

In his comprehensive psychooncology text, Holland (1998) includes two perspectives on the role of spouses in the cancer experience. In the section on the psychosocial adaptation of cancer survivors, the author gives statistics for marriage survival after a cancer diagnosis and describes "cancer-related problems" in those marriages that remain intact (Kornblith, 1998). In the

section on the family of the cancer patient, the author includes one paragraph on spouses, focusing on the "emotional and functional disruption" experienced as a result of the cancer (Lederberg, 1998). Note that in the same text, three pages are allotted to marital status as a structural measure in determining mortality, incidence, survival, and recurrence.

Since most psychooncology sources pay little attention to the subject of the spouse and his/her instrumental role, it is not surprising that virtually no attention is paid to the unique situation of the young, newly-married couple.

Cancer and Young Adults

Throughout the literature on psychooncology research and practice, the impact of cancer on young adults is discussed with varying degrees of assiduity. Lambley (1986), for example, in his work on the psychology of cancer, briefly mentions prevention as the only relevant issue for the younger adult age group. Holland & Zittoun (1990) include the topic of age only insofar as it relates to patient information-seeking and treatment choice. Barraclough (1999) includes a short mention of how younger patients may suffer more distress because they have more to lose. Holland (1998) discusses many psychosocial variables in relation to cancer but includes only brief references to age.

Research studies on the impact of cancer on young adults represent another gap in the literature. Early studies tended to focus on young adults only insofar as they represented an opportunity to assess the psychological impact of pediatric and adolescent cancer (e.g. Googan et al, 1979). In 1992, Zeltzer, discussing the need for "understanding the psychosocial sequelae of cancer diagnosed during adolescence or young adulthood", called for more studies in which this "unique population" is the focus (p. 3467). In a 1997 study, it was still being noted that "few studies...have focused on the unique stresses and life changes experienced by the youngest adult survivors of cancer" (Roberts et al, 1997, p. 16).

In 2000, Baider & Kaplan De-Nour, in the most recent of an extensive series of research

studies on cancer and spousal distress, stated decisively that "age and education have little, if any, effect on psychological distress" (p. 47). Many studies, however, have shown that the experience of cancer for young adults may be more stressful than for older adults. Ganz et al (1985), for example, reported that young adults had more frequent and severe psychological problems. Mor et al (1994) found that although younger adults were less physically compromised than older adults, they manifested a lower quality of life and less emotional well-being. Roberts et al (1991) reported higher levels of psychological distress in younger women with gynecologic cancer than in older women. And Vinokur et al (1990), in an examination of age-related distress in specific diagnostic groups of breast cancer patients, found that younger women were more psychologically distressed than older women.

Clearly, then, the age at which cancer occurs can be considered a significant antecedent factor which can influence the cancer experience; indeed, Northouse et al (1998) commented that "among demographic variables, younger age has been associated most closely with increased distress following a breast cancer diagnosis" (p. 38). Rowland (1989), in observing that social isolation is a pervasive danger in the young adult age group, attributed this risk to the fact that "the stigma of cancer is often keenly felt in this population" (p. 30). Studies that have investigated the issue further have hypothesized or inferred that certain psychosocial factors may account for the elevated levels of distress in younger patients. Cassileth et al (1984) speculated that older patients may have reduced expectations of wellness and more experience in coping with traumatic life events, thus enabling more effective adjustment to illness. Ganz et al (1985) found that younger adults were faced with more work-related problems and financial concerns than older adults. And Mor et al (1994) surmised that less financial security and more familial demands may compromise younger adults' ability to cope with cancer.

Most studies such as the above, however, define "younger" adults as younger than 50 to 65 years of age; these studies, therefore, can be more accurately said to provide research data on middle-aged adults with cancer. Notable exceptions include Cella & Tross (1986), who matched

young cancer survivors with age-matched healthy controls and found that the cancer survivors had more marital-, work-, and health-related psychological concerns; Fobair et al (1986), who found a high incidence of fatigue-related depression in younger adults, as well as significant levels of marital, sexual, reproductive, and career stress; and Friedman et al (1989), who observed that although young adults with cancer experienced no greater levels of loneliness than healthy controls, those who were unmarried had higher loneliness scores than all other subjects.

Throughout the 1990s, research on younger adult cancer survivors continued to be neglected. Roberts et al (1997), citing the need for a research-grounded intervention for young adults, studied 46 cancer survivors aged 22 to 35 years, most of whom were married or cohabiting. As measured by three assessment scales, participants rated health/recurrence, having/raising children, finances/security, and future/life goals as their most pressing concerns. Interestingly, the data did not support previous findings that younger people experience more psychological distress than older people; as the author notes, however, comparability is problematic given the widely differing definitions of "younger" and "older" that continue to be found in the research literature.

Adult Development Perspectives

As with individuals and multiple-member families, the dyadic marital relationship is vulnerable to the effects of serious illness on the life course. This marital life course arises from its particular history, is guided by shared values and goals, and manifests itself in continuity over time (Weihs & Reiss, 2000).

Although there is no universal model of adult development, several theoretical frameworks are in general use (Erikson, 1968; Levinson, 1986; Neugarten, 1968; Vaillant, 1977). In general, these approaches assume that adults, like children, undergo continuing development through a series of life cycle stages, with opportunities for emotional growth and/or developmental tasks characterizing each stage.

Within the psychooncology field, Rowland (1989) presents a detailed analysis of the adult

developmental model as it might apply to young adults with cancer. Defining young adults as aged 19-30 years old, the author discusses developmental tasks, common tumors, altered relationships, dependence/independence, achievement disruptions, body image and integrity, existential issues, and interventions. This thorough treatment of the subject of young adults and cancer, while unidimensional in perspective, is one of the few psychooncology resources to devote attention to the subject.

As maintenance of the life course is seen as the preeminent goal, Rowland's approach to the cancer experience focuses on how the experience of cancer is integrated into the young adult's developmental progress. Integration is seen as a function of adaptation, by which such challenges as emotional support and containment, informational needs, communication, practical caregiving, monetary costs, stability, and continuity are negotiated within the social matrix. Attention is paid to life cycle stages, family history, and social organization. Indeed, Rowland sees maintenance of interpersonal relationships as the central challenge for young adults with cancer, maintaining that "the patient's core relationships with intimate friends and relations require special attention" due to the "intense interpersonal and social demands of this developmental period" (p. 31).

In spite of the above, Rowland devotes very little space to discussing how cancer and marriage might impact the developmental journey. It is instructive that what she does have to say is couched in far from positive terms:

...the physically healthy partner may seriously question commitment to a person with cancer. Even a close, established relationship is strained because of fear and guilt about the potential consequences of the illness (fatality, disability, and dysfunction). The individual may opt to remain emotionally isolated rather than deal with the real or perceived demands of maintaining [the relationship]. (p. 30)

Other developmental viewpoints include those of Zeltzer (1992), who observes that an individual diagnosed with cancer in early adulthood must gather the resources to cope with the experience while "accomplishing the tasks unique to this developmental period, tasks such as the accomplishment of economic and emotional independence, capacity for intimacy, solidification of

career goals, and formation of a comfortable identity" (p. 3463), and Sourkes (1982), who characterizes the young adult's experience of life-threatening illness as one in which "the open horizons of the future are sharply delimited" and warns that close caregivers may "retreat dramatically" or show "inappropriate involvement" (p. 26).

In his discussion of illness and its impact on couples, Rolland (1994b) characterizes the young adult period as the most susceptible to trauma. Since most individual and shared goals and dreams have yet to be lived out, the sense of loss is acute, and "both need to face the limits imposed by the [illness] in relation to each life cycle goal" (p. 343). Rolland also discusses the dangers of peer group isolation, noting that the young couple with cancer and their young adult friends can easily fall into a pattern of reciprocal avoidance.

In her early work on developmental theory, Neugarten (1969) noted that throughout history human theorists have placed undue focus on continuity rather than change. Developing this idea further, Gergen (1977) proposed three orientations to the study of human development: stability, ordered change (as represented by epigenetic models such as psychoanalysis and social learning theory), and the aleatoric model, which presumes life to be an open system vulnerable to unexpected, often adverse, events. Although this developmental perspective, and the related field of chaos theory (Gleick, 1987), might be particularly relevant to young adults, no research data is as of yet available.

The Systems Perspective

Each marriage, with its network of friends and family, represents a unique relational system (Beavers, 1985). It has long been established that a cancer diagnosis reverberates throughout this system and often necessitates significant psychological adjustment and role adaptation (Cassileth et al, 1979; Ell et al, 1988; Johnson, 1988; Lewis, 1986; Northouse, 1984; Oberst, et al, 1989; Pederson & Valanis, 1988). The introduction of cancer into the system can influence such marital outcomes as mental health and role function (Baider & Kaplan De-Nour, 1984).

As the newly-diagnosed person and his/her spouse and loved ones struggle to deal with the intrusion and make sense of it, the marital and/or family system commonly perceives the cancer as a threat to the system (Weihs & Reiss, 2000). Each individual sees this exogenous threat differently, but most will perceive some possibility of disruption, unknowability, pain, separation, and/or loss. Each system member's perceptions, which may change throughout the course of the cancer experience, influence and interact with the perceptions of other members.

When challenged by a serious illness such as cancer, most systems react to the threat by trying to gain mastery over the situation (Rolland, 1994a). Typically, coping mechanisms or "regulatory behaviors", chosen from a set of constructs held by each spouse individually and within the marriage, are put into place to deal with changes affecting the system. At the same time, another set of constructs is at work shaping how the marriage system sees itself and presents itself to the outside world. This latter concept, which has been called the "organizing principle" (Steinglass & Horan, 1987) or "sense of coherence" (Antonovsky & Sourani, 1988), will determine the "delimited number of themes" (Papp & Imber-Black, 1996) around which the spouses will organize their marital identity and in turn choose their coping behaviours.

Holland (1998), one of the few sources that treats the subject of the impact of cancer on young couples as a systems issue, includes this paragraph in his discussion of family development stages:

The newly married couple must create a new system, while still dealing with issues of separation from their families of origin. Cancer in one of them may shatter the union, propelling the patient back into dependency on parents, with frequent frictions and a tendency to exclude the spouse. Acute problems may arise when the family wants to assume decision-making prerogatives that legally belong to the spouse. (p. 985)

Another theoretical perspective has been proposed by Rolland (1994b) with his Family Systems Illness Model. In this approach, the fit between the psychosocial demands of the illness and the marital functioning style is the prime outcome determinant. Adjustment is seen to take place within three dimensions: psychosocial effects, phase determinants, and marital variables.

On an even more sophisticated level, the threat of cancer to the marital system can be understood within Weihs & Reiss' (2000) model of the "cancer-related system", based on von Bertalanffy's (1968) seminal systems theory. In the cancer-related system, a hierarchy of cancer-related sub-systems or levels of organization combine to both create and cope with the cancer-related threat. These sub-systems include marital and extramarital relational processes, family legacies of dealing with illness, cancer type and treatment, and social stratifications such as financial position, religious beliefs, and community status.

Attachment Theory

Based on Bowlby's (1969) pioneering work, attachment theory, as applied to adults, concerns itself with "the maintenance of a mutually reinforcing relationship with a particular other adult" (West et al, 1986, p. 204). Within this theoretical framework, marital relationships can be seen as attachment schemas. A spouse with an insecure model of attachment would expect and/or perceive misunderstanding, criticism, rejection, and so on in response to his/her needs arising from the cancer diagnosis (Bretherton, 1988; Levitt et al, 1994), and would thus limit self-disclosure and help-seeking (Mikulincer & Nachshon, 1991; Simpson et al, 1992).

The above pattern of orientation has been described as an individual's "attachment style", and has been defined as a person's way of relating to an attachment figure who provides "the subjective potential for physical and/or psychological safety and security" (Berman & Sperling, 1994). Attachment processes can also be seen as the substrate from which other relational processes are developed. In Wynne's (1988) epigenetic model, events of becoming build upon previously occurring events, thus determining the potentialities of the next phase. Secure attachment processes within this model would include attachment/caregiving, communication, joint problem-solving, mutuality, and intimacy.

It can be readily seen that a diagnosis of cancer might affect any or all of these attachment processes. A study by Wilson (1991) illustrates this point. Men whose wives had developed

breast cancer reported feelings of intense alienation from their wives but did not share their feelings, thus leading to a kind of "pseudomutuality" in which the appearance of mutuality was maintained but a secure and responsive basis for mutual understanding had been lost. This pseudomutual solution to the challenge of cancer resulted in an insecure attachment relationship, and thus led to misunderstanding and isolation.

Insecure relational processes such as the above fail to provide a "holding environment" in which the trauma associated with cancer can be shared and relieved. Each inadequate caregiving exchange then has a cumulative destructive effect on the relationship. It is important to note that even secure attachments can be threatened when disease severity is high (Weihs & Reiss, 2000). Many marital relationships, of course, enjoy secure attachment processes, which are activated and reinforced through the sensitive responsiveness of each spouse to the other. In either case, it can be seen that there is some degree of cancer-related transformation of the marital attachment relationship.

It must also be noted that a spouse's working model of attachment will influence his/her perception of the degree of commonality of the cancer experience. The uniqueness of the experience, along with sociocultural attitudes, can leave even the most well-adjusted individual feeling isolated. To a spouse with an insecure attachment style, however, this uniqueness can turn into an alienating force, as the spouse with cancer constructs a protective wall to keep out the spouse who "cannot understand" (Rowland, 1989).

In summary, it is clear that because the experience of cancer is such a life-altering one, it almost always brings about changes in attachment relationships. Given the need for the safety and security of support that cancer occasions in most individuals, it would appear that attachment theory could be highly relevant to psychological processes in the cancer experience setting. When cancer occurs in a young adult marriage, at a time when the attachment bond is not fully formed, one might surmise that these changes would be even more challenging. It appears, however, that this topic has not been investigated.

Stage Theories

Several oncology writers have theorized that the adaptation process of the cancer patient is best understood as a succession of stages or phases. Kübler-Ross' (1970) early six-stage model of denial, isolation, anger, bargaining, depression, and acceptance, while designed for the terminal illness situation, has applications to any cancer diagnosis. Weisman (1979), one of the earliest theorists in the area of psychosocial cancer stage theory, postulated four descriptive stages of cancer: the "existential plight" stage, the "mitigation and accommodation" stage, the "decline and deterioration" stage, and the "preterminality and terminality" stage. Massie & Holland (1989) proposed a three-phase response model, with phase one consisting of shock, disbelief, and denial, phase two progressing into anxiety, depression, anger, and guilt, and phase three culminating in adjustment. Bolund (1990) divided the cancer experience into shock, reaction, work through, reorientation, and survivorship phases. And Sales (1991), like many stage theorists before her, linked psychosocial impact phases to the six sequential biomedical categories of diagnosis, hospital, post-hospital, adjuvant treatment, recurrence, and terminality.

As of yet there has not been any work done on how stage theories and the marital relationship might interact in the context of a life-threatening illness. The concept of stage theories has, in fact, waned in popularity, as observers realize that "people who experience chronic or life-threatening disease do not necessarily pass through phases which can be neatly defined" (Little et al, 1998, p. 1490.)

Relationship Perspectives

The intimate connection between marriage and illness is seen in the familiar wedding vow "in sickness and in health", with its attenuated meanings of constancy, commitment, security, loyalty, and sacrifice. It is probably true, however, that most young couples have not considered what life would be like if a serious threat to life occurred.

Although some marriages break up as a result of cancer, most do not (Cutrona, 1996;

Kornblith, 1998); in fact, studies report an increase in love and affection after the cancer experience (Swensen & Fuller, 1992) and increased or unchanged marital satisfaction (Laverly & Clarke, 1999). Various strategies have been shown to preserve marital soundness, including open communication, equity shifting, positive attribution, moral obligation, and idealization (Thompson & Pitts, 1992).

Serious illness changes the context in which a marriage is situated. The interdependence which previously was viewed as normal and desirable may now be inadequate or oppressive (Cutrona, 1996). A delicate balance must be struck between coping with illness demands, ongoing responsibilities, and relationship needs (Coyne & Smith, 1991). Deleterious effects on communication may arise from misunderstandings and unspoken thoughts (Dunkel-Schetter & Wortman, 1982; Lichtman et al, 1987). These dramatic shifts in the relationship often necessitate the creation of a whole new version of marital relating (Thompson & Pitts, 1992).

With some exceptions (Coyne & Smith, 1991; Jaffe & Jordan-Marsh, 1983; Patterson, 1989; Ross et al, 1990) the impact of illness on marriage has not been extensively investigated by theorists. Rolland (1994b) has proposed a normative framework that addresses the special concerns of marriages facing a serious illness or disability. Noting that the subject is a largely neglected one, the author uses the term "skews" to describe the adaptive changes required, as these changes can shift the marital structure out of its usual alignment. Incorporating a comprehensive, multidisciplinary approach, Rolland categorizes the issues facing spouses as "whose problem is it", "boundary issues", "patient-caregiver roles", "togetherness/separateness", "psychosocial recovery", "cognitive impairment", "gender" "sexuality", "belief systems" and "life cycle" (p. 328). He sees intimacy and communication as the two grounding concepts for realigning the skews, and notes that life cycle adjustment challenges will be more evident in the young adult age group than in other age groups.

As in the above example, the special psychosocial issues pertinent to newlywed and early marriage couples are almost invariably discussed within a developmental framework. Among more

relationship-centred contributors, Newton & Kiecolt-Glaser (1995) considered early marriage from the standpoint of changes in relationship quality, noting that "conflictive interactions" are the central factor in declining marital quality during this stage. Central among these interactions are poor conflict management skills, invalidating interpersonal styles, and hostile communication (Markman & Halweg, 1993). Indeed, it has been found that such socioemotional behaviours are more consistently related to marital quality than are variables such as degree of companionship, marital role performance, or amount of activity involvement (Huston et al, 1986). The theoretical basis for all of these approaches is that adjustment for this marital stage depends first and foremost on successful interpersonal resolution of communication and intimacy issues (Markman & Halweg, 1993; Rolland, 1994b).

Lambley (1986) is one of the few theorists who have addressed the question of how marriage type might influence the cancer experience. Three types of relationships are identified: the "status-quo maintaining relationship", the "supportive relationship", and the "radical relationship" (p. 75). In another source that develops this idea, Peteet & Greenberg (1995), discussing marital crises in oncology settings, present the effects of crisis from within a marriage typology framework, dividing at-risk marriages into "the immature relationship", "the hostile dependent relationship", "the abusive relationship", and "the estranged relationship".

Existential-Phenomenological Perspectives

The courage to endure, and the ability to transcend, an illness such as cancer is often found in the discovery of personal and interpersonal meaning. As Frankl (1984) observed, "man's search for meaning is the primary motivation in his life" (p. 121). Often, however, it is not until an individual is faced with an existential trauma such as cancer that this primary striving is activated.

The intimate, unique, and specific meaning that can be illuminated through facing a life-threatening illness "transfers vital significance from the person's life to the illness experience" (Kleinman, 1988, p. 31). For many the search for meaning will converge with an inner dialogue on

mortality and a newfound dedication to a purposeful life; for others, the search brings no answers, and thus becomes a struggle to find the courage to live without answers (Attig, 1989).

It is these profound questions of experience and meaning that are the concern of the existential-phenomenological approach to the meaning of cancer. Serious illness has a deeply private significance, provoking questions about the meaning of one's existence and creating new layers of phenomenological depth. As Plato observed, "if you want to know yourself, practice dying", for it is thought that only a confrontation with the inevitability of one's own death can provide true knowledge of what is meaningful in life.

Life-threatening disease, and the death it portends, have of course been the subject of philosophical, religious, and artistic musings for centuries, but it was not until the 1970s that psychology and sociology turned their full attention to the meaning of this universal experience. Kübler-Ross (1970) brought the experience of life-threatening illness into the mainstream. Lipowski (1970) identified the eight major meanings of disease in Western culture as challenge, enemy, punishment, weakness, relief, strategy, loss, and value. And in their seminal work, Weisman & Worden (1976) established the response to a cancer diagnosis as an "existential plight".

In the 80s and 90s, the influence of social constructivism fostered the acceptance of illness and medicine as socially embedded concepts. Kleinman (1988), defining illness as "a transactional communicative experience", notes that "illness meanings are shared and negotiated". Such socially constructed meanings of illness include family understandings of illness, a legacy that has been shown to contribute more strongly than such factors as disease severity or socioeconomic status to the illness process (Arpin et al, 1990). Relationship patterns which appear during illness can be mirror images of patterns in previous generations of the family (Penn, 1983). And the occurrence of illness in the family during an individual's childhood or adolescence can inculcate negative meanings about illness and have a long-term injurious influence on adult functioning (Wellisch et al, 1991, 1992).

Over the years, the concept of personal meaning has been examined from many

perspectives, but in general it has come to refer to an individual's sense of purpose and identity in relation to events, relationships, and ideas that are personally significant (Cassell, 1982; Frankl, 1984; Houldin, 2000). The process of meaning construction is primarily a cognitive phenomenon, arising in response to specific events and central to the process of adjustment to everyday existence (Mead, 1934), but emotions are also tied closely to meaning, in that they can be seen as "barometers of meaning" (Carlsen, 1988).

It has been said that illness cannot fully be understood without a consideration of meaning; as Toombs (1992) puts it, "the assignment of meaning and explanation is as much a part of the illness as its physical expression" (p. 104). Meaning is also a fundamental dimension of self-identity that must be understood if any understanding of the individual's concept of illness is to be gained (Cassell, 1982). The process of meaning-making is a dynamic one, adapting to changes occurring in the individual, in the course of the illness, and in the sociocultural context (Fife, 1994; Frankl, 1984; Kleinman, 1988).

We have seen that the biomedical and biopsychosocial approaches to cancer, with their emphasis on pathology and distress, have contributed much to our socially constructed meanings of cancer. One only has to hear the word "cancer" to begin imagining a constellation of ideas and images. Sontag (1978) has vividly described how the fatal and mysterious image of cancer, the "demonic pregnancy", has become a widely used metaphor for evil in modern society. Advances in medical treatment have not ameliorated the public perception of cancer as a fear-provoking, death-associated disease (Levin et al, 1985; Silberfarb & Greer, 1982; Slaby & Glicksman, 1985; Pinell, 1987). As Dreifuss-Kattan (1990) has observed, "no other disease attracts to itself such a wealth of personal symbols and metaphorical equivalencies" (p. 12).

It is not difficult to see why cancer has become, as Gregory & Russell (1999) observe, "etched in bodies, written into the plots of life stories, and woven into the social fabric of our times" (p. 1). The unique signature of cancer is perhaps its association with suffering, with its concomitant terrors of pain, metastasis, cachexia, and fatality, the latter always envisioned as an agonizing,

lingering death; as Pinell (1987) says, "cancer condenses all the characteristics of an unforgettable horrible death" (p. 27).

If illness is the "perfect symbol of the complete destruction that will leave nothing intact" (Leger, 1999, p. 210), then cancer is surely the most perfect embodiment of that symbolism, from the cutting, burning, and poisoning of treatment to the promotion of the "war on cancer". Patterson (1987), in calling cancer "the dread disease", reflected an enduring schema that, like most of the literature on cancer, is saturated with images of infiltration, voracity, destruction, mutilation, catastrophe, horror, and death. Given the overwhelming influence of the above images and meanings, and given that much of the cancer experience takes place in biomedical venues such as doctor's offices, clinics, hospitals, and laboratories, it can be seen that most personal searches for meaning occur within an environment that is anything but conducive to reflection and self-discovery. As Kleinman (1988) says, the biomedical system replaces the search for meaning, a "devalued psychosocial concern", with symptom control, thereby achieving a "pernicious value transformation" (p. 9).

In spite of the meaning-making power of the biomedical paradigm, increasing interest has been directed in the last three decades to the concept of personal meaning as it might relate to cancer and other life-threatening illnesses. Important theoretical work has laid the foundation for this avenue of inquiry, suggesting that the search for meaning is a significant dimension of response to life-altering events (Antonovsky, 1980; Frankl, 1984; Marris, 1974). Many qualitative studies have provided empirical evidence of the importance of meaning by describing its role in adjustment and outcome (Barkwell, 1991; Fife, 1994; Germino et al, 1995; Luker et al, 1996; McGrath, 1998; O'Connor et al, 1990; Steeves, 1992). And assessment tools such as the Constructed Meaning Scale (Fife, 1995) and the Illness Constellation Model (Morse & Johnson, 1991) have been developed to operationalize the concept of meaning as it is constructed within the context of life-threatening illness.

Much of the work done in the field of cancer and meaning has relied on the significant

contributions of attribution theory, based on Heider's (1958) view that individuals attribute causal connections to events in their lives in order to make sense of them. The process of causal thinking begins with the question "Why did this happen to me?", guides the individual through the course of the illness, and produces an outcome that is based on the causes, or personal explanations, generated by the attributional search (Lowery & Houldin, 1996; Weiner, 1985). Cunningham (1992) has given us a comprehensive description of the search for meaning that accompanies the cancer experience:

The search for meaning in cancer...is the attempt to place it in its physical, psychological, social, and spiritual context; growing understanding may or may not be accompanied by physical healing, but will bring comfort, an awareness of our connectedness, a lessened fear of death, and a sense of authenticity and purpose in life. (p. 142)

Most psychooncology sources do not include the subject of meaning as a topic for therapeutic inquiry. As might be expected, those that do address the issue place it within the distress framework discussed earlier. Maguire (1990), for example, includes one paragraph on meaning which begins "Here, patients feel anguished because they cannot find an acceptable explanation for their disease..." (p. 68). Bolund (1990) warns that the search for meaning may cause the patient to be "lost, depressed, or confused", so that "it is not uncommon that patients will need anti-depressant medication" (p. 20). Tope et al (1993), in delineating the factors that promote psychological well-being and quality of life for cancer patients, do not mention meaning at all.

The primary impetus for the search for meaning is to create a sense of congruence between the individual's sense of identity and the illness event (Thompson & Janigian, 1988). For most individuals, this involves a reconstruction of one's personal meaning structures, on the basis of what is important and meaningful in that person's life, to accommodate the critical life event (Fife, 1994). Thus the search for meaning can be a valuable part of the coping process (Fife, 1994; Lipowski, 1970), while the "found meaning" is a positive aspect of the coping outcome (Thompson & Janigian, 1988).

What constitutes meaning will, of course, vary greatly among individuals. For many the

search will be rooted in religious faith, as many belief systems emphasize the importance of looking within through prayer and meditation to find answers. Positive meanings can be found in seeing the illness as a challenge to overcome, as an opportunity for self-growth, as a reminder of the fragility and preciousness of life, or as a catalyst for lifestyle change (Houldin, 2000; Taylor, 1989). Often meaning is found in an existential shift of self-identity, as the individual grieves his/her pre-cancer persona (Lewis, 1989), recreates a sense of wholeness and personal integrity (Fife, 1995), and accepts the irreversibility of the life course (Frankl, 1984). Those who search and find only negative meaning, such as ideas of punishment, weakness, or malediction, may experience heightened distress and have difficulty coping (Barkwell, 1991; Wortman & Silver, 1992).

Although there is evidence that some individuals diagnosed with a life-threatening illness do not engage in a search for meaning (Lowery et al, 1987; Taylor et al, 1984), and even that these individuals may be less distressed (Lowery et al, 1987), most recent research studies have established that finding a positive sense of purpose in the cancer experience is associated with adaptive coping (Barkwell, 1991; Coward, 1991; O'Connor et al, 1990). These findings confirm Frankl's (1984) observation that if an individual's search for meaning is successful, it gives him/her greater ability to cope with suffering.

As Fife (1994) has noted, there has been relatively little study of the impact of personal meaning on coping, behaviour, and adaptation to illness. As might be expected, there has been even less work done on the meaning of cancer for spouses, both individually and as a marital dyad. Taylor (1983), using attribution theory to study meaning as it relates to couples experiencing breast cancer, found that 95% of the women and 63% of the men had made a concerted effort to understand why the cancer had occurred. Taking her findings a step further, Taylor observed that the attributions made by her subjects pointed to a link between the meanings assigned to the experience and the struggle to develop a sense of mastery.

Germino et al (1995), using a combined qualitative and quantitative approach, studied the meaning and significance of cancer for the partner relationship. Interview data indicated that both

partners search for meaning in an attempt to decrease the threat of cancer; the most prevalent themes identified were day-to-day adjustment and intimacy concerns. The researchers also noted that "the more positive the meaning constructed by the individual the more positive their general psychological adjustment, and their adjustment within the family and the dyad" (p. 49).

Narrative Perspectives

There can be little doubt of the centrality of narrative to the culture of medicine and the experience of illness. From the ancient oral transmission of healing rituals to the modern sharing of case reports, narrative is fundamental to the everyday accomplishment of medical work. At the same time, individuals often feel the need to describe and explain their suffering in the face of illness, thereby using the story as a way to order the illness experience into a coherent, meaningful form. As Brody (1987) observes, there is an ongoing dynamic between medicine as storytelling and storytelling as medicine.

As postmodern, social constructivist views have taken hold across a broad spectrum of disciplines, many theorists have contributed to an expanding awareness of the subjectively lived nature of the illness experience. The early theorists Berger & Luckman (1966) portrayed the relationship between biological and cultural factors as a continuous dialectic between the phenomenological experience of embodied life and the detached, socialized awareness of the body as object. Foucault (1989) described how the "clinical gaze", or the impersonal, dissection attitude of Western medical clinicians, represents a disempowering discourse associated with social control. Field analysts have shown how medical diagnoses can be viewed as nothing more than socially constructed narrative interpretations (Barrett, 1988; Taussig, 1980; Waitzkin, 1991), which are then reinforced by the iterative nature of medical communication and practice (Stainton-Rogers, 1991). And a growing number of theorists are now presenting material on the use of various discursive methods to understand the individual meanings of illness found in personal experience (Auge & Herzlich, 1995; Crossley, 1999; Frank, 1998; Good, 1994; Katz & Shotter, 1996; Toombs, 1992;

Yardley, 1997).

Although the power of narrative has long been recognized in psychiatry, with Freud deemed a master of the narrative tradition (Spence, 1982), it is only just beginning to be recognized in other medical disciplines. Sacks (1987) has been an influential advocate of this new paradigm in medicine, which seeks to make the "suffering, afflicted, fighting human subject", rather than the disease, the central character in the clinical conversation; to achieve this, Sacks believes that clinicians must "deepen a case history to a narrative or tale" (p. viii). Hardey (1998) has noted that changes in doctor-patient discourses have led to the redefinition of patients as "experienced subjects who can contribute knowledge and take an active part in decisions" (p. 84). A growing number of practitioners has argued that doctors must realize that there is more to being a patient than is captured in clinical interpretations (Broyard, 1992; Coles, 1989; Frank, 1995; Hahn, 1995; Hunter, 1991; Kleinman, 1988).

By applying narrative theory to medicine, the doctor-patient relationship, for so long characterized by "conflict and struggle between two different domains of meaning" (Mishler, 1984, p. 121), is now to be one of collaborative meaning-making; as Eisenberg (1981) sees it, "patient and doctor together reconstruct the meanings of events in a shared mythopoesis" (p. 245). Charon (1993) notes, "What, in fact, do doctors and patients do together but to create between themselves a many-staged narrative?" (p. 87). By seeking clinical advice, the patient essentially proffers an invitation for interpretation; the doctor then serves as both listener and interpreter in a process of clinical hermeneutics (Daniels, 1986; Leder, 1990).

It has been suggested that the compatibility between narrative and illness is grounded in the suitability of the narrative structure for incorporating adversity into the life story. Adversity, defined as "an unpleasant, unexpected event leading to a crisis of meaning" (Cohler, 1991, p. 183), seems to be a major organizing factor in all personal narratives from a very early age (Miller & Sperry, 1988; Peterson & McCabe, 1983). The way in which adversity is met in early life is a critical factor in the shaping of later outcomes (Erikson, 1963; Lorenz, 1965). And in reviewing the plenitude of

definitions that have been used for the term "story", Stein & Policastro (1984) found that adversity is a common theme among both children and adults.

In developing this theory, Cohler (1991) pays particular attention to how adversity in the form of "early, off-time, adverse life-changes" (p. 184) is incorporated into life stories. Identifying a "major health problem" as one of these dissonant events, he shows how narrative acts as a way to integrate the solitary adverse event into a less adverse whole, thus dismantling its power and allowing the preservation of continuity and coherence over time. A parallel approach is taken by Becker (1997), who has shown that a major disruption in life can mobilize narrative's potent constructive capacity, allowing a reconstruction of self and the self's place in the world. It appears to be only unanticipated adversity or disruption, such as a cancer diagnosis at an unexpected point in life, that provides the dramatic quality or tension that Bruner (1990) sees as the essential organizing principle of narrative reorganization. Successful resolution of this tension or adverse event, by rendering the experience once again canonical, bolsters personal resilience, vitality, and mastery and creates a sense of biographical continuity (Becker, 1997; Hunt, 2000).

The narrativization of adverse events such as an unexpected illness, then, allows the individual to "make sense or manage meanings of adversity" (Cohler, 1991). These meanings are often embedded in stories that draw upon historically grounded family and cultural meanings (Seaburn et al, 1992). Reactions to cancer have been shown to be powerfully affected by the meanings that families have ascribed to illness through multigenerational narratives (Sherman & Simonton, 2001; Walsh, 1998). An illness narrative, therefore, will reflect not just an episodic recounting of symptoms and reactions but also a personal interpretation that is firmly embedded within sociocultural realities, all of which together constitute what Mishler (1984) calls the "lifeworld" of the patient.

By enabling the individual to objectify and externalize, and hence communicate, the phenomenological realities of the experience, the illness narrative is used to "give credence to the distinctive events and long-term course of suffering" (Kleinman, 1988, p. 49). These realities often

remain abstruse and unformed until the narrative process releases them, at which time the story, as creative vessel, can become "the container for all the shifting emotions, especially fear and grief, that are experienced in the course of the illness and treatment" (Dreifuss-Kattan, 1990, p. 4).

In the act of verbalizing the experience of cancer, the narrator is also able to intimately relive the experience and yet achieve a certain therapeutic distance from it, thus being both the main protagonist of the story and a reflexive observer (Bruner, 1986). In this way, the storyteller reevaluates the cancer and the existential trauma it provoked and is able to "battle against the feeling that the cancer is totally senseless and deprives life of meaning" (Dreifuss-Kattan, 1990, p. 5).

Mathieson & Stam (1995) show how this process serves as more than just a self-affirmation:

For cancer patients...stories have a special meaning. In negotiating their way through regimens of treatment, changing bodies, and disrupted lives, the telling of one's own story takes on a renewed urgency. In the end, they are more than just stories but the vehicle for making sense of, not just an illness, but a life. (p. 284)

In making sense of cancer, cancer narratives transform the lived knowledge of the cancer experience from the liminal to the actual and are thus a valuable gift with great pedagogical potential (Gregory & Russell, 1999). The value of knowledge embedded in experience has long been recognized (Gadamer, 1975; Heidigger, 1962); with more and more clinicians recognizing the value of patient stories, it is anticipated that the medical clinic will turn its orientation from the "clinical gaze" towards more nuanced and compassionate listening. As Charon (1993) puts it, the hope of the narrative model of medicine is to "redefine the clinical enterprise in ways that lead to deeper understanding and more effective care" (p. 95).

Psychotherapeutical Intervention

Although it has been said that "it is by no means taken for granted that oncology counseling is desirable or necessary" (Goodare, 1994, p. 4), many oncology writers and researchers have cited the benefits of intervention for cancer patients and their caregivers (Fawzy, 1994; Fellowfield, 1988; Golden et al, 1992; Goodare, 1994; Gordon et al, 1980; Henderson, 1997; Houldin, 2000; Rowland, 1994; Sherman & Simonton, 1999; Worden & Weisman, 1984). Acceptance of counselling for

cancer patients, however, has been hindered by the influence of the biomedical community, as is evident in O'Boyle's (1993) comment that "the Cartesians among us find it enormously difficult to accept the possibility of any psychological influences on diseases that are as obviously organic as cancer" (p. 126). Some highly visible advocate-researchers have alienated medical oncologists by linking counselling with improved survival rates (LeShan & Gassman, 1958; LeShan, 1989; Spiegel, 1991), an issue that remains controversial and unsettled.

By the 1990s, psychotherapeutic counselling for cancer patients had been fairly widely accepted, with Holland's (1998) psychooncology text covering crisis counselling, psychoeducational interventions, group therapies, cognitive-behavioural interventions, art therapy, telephone counselling, meditation, spiritual approaches, bedside interventions, alternative strategies, and rehabilitation counselling. Sufficient empirical work was available to allow the publication of clinical reviews and meta-analyses (Devine & Westlake, 1995; Fawzy et al, 1995; Meyer & Mark, 1995). An important direction for future counselling has been brought forward by Henderson (1997), who notes that with improved cancer survival rates, interventions will need to be geared more towards survivors than towards patients.

Psychosocial intervention has been defined as the "systematic efforts applied to influence coping behaviors through educational or psychotherapeutic means" (Massie et al, 1989, p. 460). The goal of psychosocial oncology care is "to understand the unique needs and strengths of the patient and family to create an individualized plan of care that promotes optimal psychological adaptation" (Houldin, 2000, p. 7).

Given the overwhelming research evidence that both spouses experience some level of psychological distress when faced with cancer, it would seem that the development of counselling interventions for spouses, both individually and as a couple, would be an area of considerable activity. Despite early evidence that intervention is beneficial (Cohen & Wellisch, 1978; Johnson & Stark, 1980), however, there has been little systematic consideration of the effectiveness of formal psychotherapeutic intervention in addressing spousal distress. As Rolland (1994b) has said, "the

particular issues for couples facing illness and disability remain a surprisingly neglected topic in the couples therapy literature" (p. 327).

In general, interventions have tended to involve a combination of support, information, and cognitive-behavioural coping strategies. Christensen (1983) used a structured counselling protocol for post-mastectomy couples; Goldberg & Wool (1985) tested a structured 12-session intervention to assist the spouses of lung cancer patients; Sabo et al (1986) examined the effectiveness of a support group for husbands of women with breast cancer; Carter & Carter (1994) reviewed their extensive work using traditional psychotherapy with patients and spouses dealing with breast cancer; Knakal (1994) described a therapist-moderated couples' support group that through group interaction and individual counselling sought to maintain homeostatic balance in the relationships; Peteet & Greenberg (1995) instructed clinicians on how to provide case-tailored interventions for "schizmo-genic", or habitually impoverishing, marriages; Blanchard et al (1996) compared the effectiveness of the Coping With Cancer intervention program for the spouses of cancer patients to the services offered by a regional medical centre's oncology department; and Horowitz et al (1996) provided an 18-month psychoeducational group intervention for spouses of patients with brain tumors.

Varying degrees of effectiveness were reported for the above interventions, indicating a need for more intervention studies, including for the unserved young adult group. Rolland (1994b), noting that cancer support groups are usually site-specific rather than age-sensitive, called for more groups "organized according to stages of the life cycle" (p. 344); Northouse et al (1998) stated simply that "clinical interventions need to be targeted toward couples" (p. 46).

Chapter III

METHODOLOGY

Existential Phenomenology

This study rests upon the existential-phenomenological approach to understanding human experience. Two strands of thought come together in this approach: existentialism, which looks for understanding through the study of lived experience, and phenomenology, which explores human awareness of experienced phenomena. Through existential phenomenology, the researcher investigates human experience in order to reveal meaning.

Why are meaning and experience so important and how do we go about creating them? As a starting point, I approach this question through the classic phenomenological writings: Husserl's (1965) groundwork in phenomenology, with its emphasis on individual consciousness and experience, Heidegger's (1962) work on the centrality of interpretation, Kierkegaard's (1959) emphasis on the striving for individual meaning against the force of societal dogma, and Sartre's (1977) call for meaningful action in the face of meaninglessness. On this philosophical foundation rest Mead's (1934) view of identity as a social phenomenon, Kelly's (1955) positing of the self as a social construct, Weber's (1958) concept of society as a network of meanings, and Berger & Luckmann's (1966) views on the social construction of reality.

The above grounding of ideas encouraged the researcher to situate herself as a recorder and interpreter of experience and meaning within the framework of subjective reality and social connectedness.

Qualitative Inquiry

Qualitative inquiry, in seeking to penetrate the research participant's subjectively lived world, is in best alignment with the phenomenological worldview described above. Comprehensive texts on the qualitative method (Banister et al 1994; Denzin & Lincoln, 1994; Koppala & Suzuki, 1999; Morse et al, 2001; Silverman, 1997) trace this connection between philosophy and method in terms

of hermeneutics, or the interpretation of meaning in text. Indeed, qualitative research can be seen as a kind of methodical hermeneutics, an instantiation of human science that brings its own type of methodological rigor to the research environment (Rennie, 1999).

Qualitative research, being inherently multimethod (Brewer & Hunter, 1989) and multiparadigmatic (Nelson et al, 1992), also supports the use of diverse research tools and interpretive paradigms. Thus the researcher can employ many different but complementary approaches, such as the case study method, narrative analysis, hermeneutical inquiry, existentialism, social constructivism, and so on, to fulfill the aim of obtaining a rich, in-depth understanding of the research phenomenon. This triangulation allows the researcher to gather a substantial amount of empirical material that will serve the qualitative aims of rigor, breadth, and depth (Denzin, 1989; Fielding & Fielding, 1986).

Another strength of the qualitative method is its flexibility. Rather than working from a rigid, predetermined plan of inquiry, the qualitative researcher approaches the research work with a certain openness, artlessness, and pliancy, what Kvale (1996) calls "deliberate naivete". This does not imply unpreparedness or indecisiveness, but rather represents a shift of focus from discovering "facts" to describing meanings and themes as they arise in the interview context. As Merleau-Ponty (1962) established, the first goal of the investigator is to describe, not to explain.

Since qualitative methodology favours data-collecting procedures that depend on intensive immersion in the social phenomenon being studied, it can best attend to the existential quest for meaning as expressed in subjective, conversational accounts of life. As Pawson (1989) puts it, qualitative researchers are "committed to understanding the respondent's 'meaning' and so regard data collection as a task for inducing everyday talk" (p. 292). It is through immersion in such "everyday talk" that the researcher can uncover meaning.

As qualitative research is concerned with obtaining in-depth research data about a particular phenomenon, subject samples tend to comprise a small number of cases chosen on a theoretical basis. Sample choice is then determined by the research question, the adopted approach to the

research, and practical considerations such as time and financial resources (Lyons, 2000). The researcher's sampling procedure was checked against Miles & Huberman's (1994) list of sampling strategies, with the study in question fitting within two categories: intensity sampling, in which information-rich cases manifest the phenomenon intensely, but not extremely, and criterion sampling, in which all cases included meet a specified criterion.

An important consideration for any qualitative researcher is to ensure that the methodology chosen has what is known as "methodological rigor", in that it can be said to be of high quality when measured against certain standards. The question of what those standards should be is still an ongoing debate in the qualitative research forum. For this study, four sources were chosen by the researcher to assess the quality of the research. First, the foundational work of Lincoln & Guba (1985) was considered, and the research weighed against their "parallel criteria" of credibility, transferability, dependability, and confirmability. Second, the work of Stiles (1993) was instructive in showing how qualitative validity can be approached as a "fit" or "agreement" between coherence validity, consensus validity, and testimonial validity. Third, Merrick's (1999) evaluation of quality in qualitative research was relied upon to test for trustworthiness, reflexivity, and representation. And from within the narrative tradition, Riessman's (1993) conceptualization of validity as evidenced by persuasiveness, correspondence, coherence, and pragmatic use was utilized as a final criteria set.

Qualitative Approaches to Illness

It is a presumption of this study that disease is not simply a biological entity, but is constituted through personal and sociocultural forces into meaningful narratives. If we are to discover the meaning of cancer for a particular participant or participant group, methods must be used that nurture the collection of rich, meaning-full data. Whereas quantitative research can only provide the etic viewpoint, qualitative research gives an emic, intimate, "insider" view of the illness being studied (Olson, 2001). As Gregory & Russell (1999) say, "qualitative research methods give priority to persons and their disease journeys" (p. 3).

It has been observed that qualitative methods have not been widely used to study cancer (Waxler-Morrison et al, 1991). There are a variety of reasons for this, but the most significant is the overwhelming influence that the positivist, objectivist biomedical paradigm has enjoyed in the oncology field. Research budgets have been, and for the most part still are, heavily weighted in favour of clinical medicine and quantitative research. As more individuals with cancer, their caregivers, and professionals focus attention on the psychosocial aspects of cancer, however, qualitative and interdisciplinary research have been increasingly legitimized.

These slow but profound changes in the praxis of scientific inquiry have come in response to the realization that our bodies, our minds, and our lives are fundamentally and intimately inseparable. Beyond biology and epidemiology, the domains of personal, aesthetic, moral, and ethical knowledge are integral to a holistic understanding of disease. It is this human side of disease that qualitative research is best equipped to describe, since it "challenges researchers to understand the cancer experience, and the suffering therein, in a more holistic manner" (Gregory & Russell, 1999, p. 4). And the qualitative data obtained from such research, because it alone contains the necessary "wealth of unique insights into the personal stories and dynamic nature of cancer" (King et al, 1997, p. 37), can best capture the cancer experience.

The Co-Researcher Approach

Working within the existential-phenomenological point of view, research interviews were seen as experiences or encounters in which both the researcher and subject were active participants. The interview became a collaboration in which the researcher was seen as a co-researcher, engaged with the participants in the construction of meaningful and accurate research data. When viewed in this way, it was apparent that the choice of such an approach is more an epistemological one than a technical one; as Sciarra (1999) says, "it is more about philosophy of knowledge and how one understands the real" (p. 37).

Four tenets of orientation were seen as fundamental to the co-researcher philosophy. First,

the interviewer as co-researcher was part of the interview in a complete and inescapable way; at no time did the interviewer become strictly an "observer" or "onlooker". Hathaway (1994) has characterized this stance as one in which the researcher is like an actor in a scene with other actors.

Second, the interviewer as co-researcher was at all times a student rather than an expert. In this way the research process became an interactive rather than a controlling one (Hamelton, 1994) and the researcher by relinquishing control was able to enter the world of the participants (Kleinman & Copp, 1993). The goal at all times was to create a truly democratic environment in which the parties were equal and the only "expertise" was that of the participants about themselves.

Third, the interviewer as co-researcher did not attempt to remain detached or distanced from the research proceedings, but rather accepted that some degree of emotional involvement would be part of the interview process. The co-researcher's empathy, described by Rogers (1959) as feeling "as if one were the other person", was considered a positive, desirable, and advantageous part of the research process. Not only were emotions allowed, they were seen as crucial to understanding meaning, for it is considered inconceivable that the co-researcher could enter the world of the participants without some emotional involvement (Kleinman & Copp, 1993). Thus, the co-researcher was free to rely on both emotion and cognition to understand as fully as possible a world of thoughts and feelings that inevitably was different from her own.

Fourth, and following from the above, the interviewer as co-researcher stayed alert for overidentification or underidentification with the participants. Although the co-researcher aims to enter the world of the participants, certain types of involvement can change the co-researcher relationship into an overly symbiotic one. Sciarra's (1999) advice was followed here: "The investigator ought to take a systematic step back from the data (and this includes the researcher's emotions and emotional involvement) to analyze and understand what such involvement is revealing about the participants' and the investigator's worlds of meaning" (p. 45). This can be accomplished if the co-researcher maintains an empathic stance in the research interaction, but then assumes a neutral stance in the analysis of the data (Patton, 1990).

Narrative Theory and Psychology

Every human experience can be seen as a story, and on this simple premise rests the narrative approach to the study of human psychology. It is in the interpretation of these stories, however, with all their richness and complexity, that the narrative researcher's true challenge lies. Since the main theoretical grounding for this study is in narrative theory and psychology, I will discuss this approach in some detail.

Along with discourse analysis, post-structuralism, and post-modernism, the narrative approach embraces the social constructivist paradigm of thought. Within this paradigm, human identity and experience are ineluctably dependent on the discourses we use to make sense of everyday life. The influential early theorists Potter & Wetherall (1987) decreed that the crucial question for researchers must be "How is the self talked about, how is it theorised in discourse?" (p. 102), and thus language and how it is used became central to any understanding of human experience.

Narrative theory shares the social constructivist commitment to the central role of language in human self-ideation, but its most fundamental assumption is that human experience is meaningful (Crossley, 2000; Garro & Mattingly, 2000). As human beings, we are essentially interpretive creatures, engaged in a lifelong process of reflecting on what is happening to us and trying to make sense of it. Narrative psychology focuses on how humans use their sense-making capabilities to interpret their individual worlds through what Polkinghorne (1988) calls "meaning systems". It is this focus on meaning and interpretation that distinguishes narrative theory, and the psychology and methodology based on it, from other approaches.

From a narrative perspective, then, "meaning" is preeminent, and can be defined as "any interpretation of experience that is related or connected in some way to something or someone else" (Crossley, 2000). Such interpretations are not produced independently, but are formulated within meaning systems such as language and cultural narrative. Thus, from a very early age, we absorb

culture-specific patterns of meaning through fairy tales, myths, and historical sagas (Bettelheim, 1976; Howard, 1991) and through family stories and cultural narratives (Langellier, 1989; McAdams, 1993).

Perhaps at this point we should take a moment to consider the term "narrative". The concept of narrative as an organizing principle in human thought has become popular in many diverse disciplines, with the result that there has been a proliferation of opinions as to what a narrative actually is. In the field of narrative theory, Polkinghorne (1988) has definitively established that a narrative is a "meaning structure that organizes events and human actions into a whole, thereby attributing significance to individual actions and events according to their effects on the whole" (p. 18). Thus narrative is the overarching concept, with "story" defined as "the set of events in their chronological order" (Bal, 1994, p. 11) and plot seen as "the intelligible whole that governs a succession of events in any story" (Ricoeur, 1980, p. 171).

A narrative can contain an infinite number and variety of stories and plots, a repertoire from which each person selects specific stories and plots according to the narrative that he/she desires to tell at that moment; as Smith (1980) explains, "for every given narrative there are always multiple basic stories that can be constructed in response to it" (p. 221). Narrative stories and plots can be categorized and placed within discrete groupings, and much work has been done on such classification systems (Frye, 1957; Gergen & Gergen, 1986; Howarth, 1980).

Whether narrative, story, plot, personal myth, autobiography, or other term is used, it is generally accepted that narration is a universal, immemorial, and irresistible creative act which speaks to the need of people of all ages and cultures to recast the experiences of their lives in a meaningful form. Although cultures may vary in respect to what is considered an acceptable narrative, the organization of life into an ordered form appears to be characteristic of all cultures (Cohler, 1991; Levi-Strauss, 1962). As Barthes (1975) observed, "Narrative starts with the very history of (hu)mankind" (p. 237). Thus narrative is an essentially human way of being in the world and of thinking about the world, a universal inclination to order events into temporal patterns and

configurations of meaning (Brooks, 1985; Carr, 1986; Danto, 1985; Freeman, 1997). Indeed, Ricoeur (1981) comments that "The form of life to which narrative discourse belongs is our historical condition itself" (p. 288).

Within this supraordination of narrative as a basic dimension of human existence, narrative has many vital purposes. The most basic purpose of narrative is as a descriptive and explicatory mechanism; indeed, Bruner (1986) states that "we seem to have no other way of describing 'lived time' save in the form of narrative" (p. 12), and Widdershoven (1993) maintains that "life has an implicit meaning which is made explicit in stories" (p. 27). In addition, narrative serves to help human beings make sense of and find meaning in reality, whether the factual reality of actual events or the symbolic reality of thoughts, feelings, and dreams; as White (1980) sees it, narrative activity is a solution to "the problem of fashioning human experience into a form assimilable to structures of meaning" (p. 5). That this is a quintessential human striving is evidenced by the fact that very young children construct narratives (Fivush et al, 1987; Miller & Sperry, 1988) and will keep doing so until old age, often in the form of a life story (Cohler & Galatzer-Levy, 1989; Kaufman, 1986).

An important function of narrative, of course, is as a communicative or dialogical medium. This dialogue is both intrapersonal, as the narrator brings together lived experience and interpretation in what Gadamer (1975) calls a "fusion of horizons", and interpersonal, as the narrator shares this construction with others. As Freeman (1997) puts it, narrative serves as a bridge between people, a way of achieving contact and understanding even across significant gulfs of time and space.

An essential function of narrative is to bring a sense of temporal ordering, continuity, and coherence to life; as Linde (1993) has said, narrative provides "not only temporal sequence and temporal continuity, but also causality" (p. 111). Even the simplest account of events, or a story which ends in a state of indeterminacy, will exhibit an attempt to put a "stamp of order upon the chaos of existence" (Ricoeur, 1980), in what Kermode (1967) has called "obligate successiveness".

Narrative also allows the narrator to construct self-identity by "storying" the self into a

certain unique configuration (McAdams, 1993); thus our very identities, predicated as they are upon the process of historical understanding, are tied to narrative (Freeman, 1993; Gergen & Gergen, 1997; Kerby, 1991; MacIntyre, 1981; Polkinghorne, 1991). Narratives provide us with personalized moral "scripts" (Arnold, 1962) that inform our moral consciousness and guide our actions in an ongoing process of dialogical moral development (Day & Tappan, 1996). Narrative provides the form for our "culture tales" (Howard, 1991) or "master narratives" (Linde, 1993), whether told in grand myths or simple proverbs. Narrative serves as a pedagogical tool, as all narratives have the capacity to explain and educate (Coles, 1989). Lastly, human emotions can be understood as "narrative enactments", in that they reveal "intense organismic involvement in the plot" (Sarbin, 1995, p. 219); as Singer (1995) explains it, "specific emotional responses in interpersonal interactions belong to the context of a wider narrative" (p. 260).

If we accept that narrative and meaning-making are central to the human experience and serve many important purposes, we must then ask: how is meaning actually constructed from narrative? Bruner (1986), expanding on the groundbreaking work of Barthes (1970), divided the meaning-making process into two modes: the paradigmatic mode, which organizes experience hierarchically into categories and concepts, and the narrative mode, which "deals in human intention and action and the vicissitudes and consequences that mark their course" (p. 13). In this narrative mode, through what Bakhtin (1981) characterizes as a continuous interplay between internal and external dialogues, meaning is organized in the form of narratives, stories, and plots. Events by themselves are of nominal interest, providing only the "episodic dimension" of the narrative (Ricoeur, 1981); it is the way in which the narrator forms the events into a complex of personalized meanings within the "configurational dimension" (Ricoeur, 1981) or "pattern of transformation" (Ochberg, 1994) that matters.

Although the process of narrative construction in the human mind is not pertinent to this study, one point is worth mentioning. It is assumed that Mandler's (1980) famous dictum "the meaning is in the text" has been superseded by the position that meaning is constructed through

social interaction and that therefore, as initially proposed by Bartlett (1932), story schemas are culture-specific and "one story map may not fit all" (Invernizzi & Abouzeid, 1995). Thus a narrative is viewed as a cultural artifact, and the researcher proceeds at all times with an underlying awareness of the social context.

Narrative Methodology

The growth and popularity of narrative inquiry has resulted in a proliferation of models and approaches. A commonsense approach to achieving some coherence out of this profusion of materials was found in Mishler (1995), who proposes a simple typology of analytical methods. Narrative approaches are grouped into three categories: referential, which focuses on the temporal sequence of events and their order of presentation in the story; textual, which studies the strategies by which types and genres of stories are organized; and narrative, which concerns itself with the contexts and consequences of storytelling. This study is grounded in the third typological grouping, in that it aims to produce what Mishler calls the "narrativization of experience".

An impressive body of narrative research studies has provided insight into the continuing process of the illness trajectory and established narrative as a leading methodology in qualitative medical research (Estroff, 1995; Frankenburg, 1986; Garro, 1994; Hyden, 1997; Mattingly, 1994; Riessman, 1990; Robinson, 1990; Steffen, 1997; Williams, 1994). Researchers have also focused specifically on cancer from within the narrative methodological framework (Bell, 1999; Good et al, 1994; Gregory & Russell, 1999; Hunt, 1994; Little et al, 1998; Saillant, 1990). And narrative methodology has been used extensively to explore the meanings of marriage (Baker & Johnson, 2000; Johnson, 1999; Ohrbuch et al, 1993; Oppenheim et al, 1996; Riessman, 1989, 1991; Veroff et al, 1993a, 1993b, 1993c; Weingarten, 1991).

Having established the suitability of the narrative method to the research topic, the next step was to select a model of narrative analysis. To that end, the researcher conducted a survey of analytical approaches which would serve the research purpose, namely to narrativize experiential

accounts of the cancer experience as obtained in semi-structured interviews. Once a comprehensive review of potential models was completed, the researcher selected those that were a good fit with the subject environment. In this instance, sources that employed narrative analysis in an illness or trauma environment were given special consideration. From the above two paths of inquiry, a working set of materials was chosen.

For analyzing the narratives prepared from the interviews, three main sources were used. Crossley's (2000) work on applying narrative methods was the major source, both because it represents a contemporary outlook and because the author has written extensively on narrative psychology and illness (Crossley, 1997, 1998, 1999). Riessman's (1993) practical, succinct work on narrative analysis was also invaluable; as with Crossley, Riessman's work with relationships and illness provided an added sensibility to the endeavour (Riessman, 1990, 1991, 1992). And Smith (1995) was consulted for his guidance on how to transform the raw data obtained in semi-structured interviews into a quality representation of thematic material. It is also important to note that Crossley's approach to narrative methodology relies extensively on McAdams (1993), whose work the researcher has used in previous narrative projects; indeed, McAdams was often consulted to supplement Crossley's guidelines. Other sources consulted as background support were Colaizzi (1978), Cortazzi (1993), Lieblich et al (1998), and Mishler (1986).

As we have seen, narrative methodology is inherently flexible, and this was borne out by how well these materials supported and complemented each other. Narrative researchers frequently apply multiple perspectives to narrative analysis in order to enrich their understanding of the data; Johnson (1999), for example, in studying courtship and marriage narratives, used analytical frames derived from different combinations of narrative analysis, conversation analysis, and discourse analysis. As Miller (1997) states, dialoguing between different interpretive frameworks allows the researcher to gain "interpretive insights, particularly into the ways in which meaning is implicated in our everyday lives and activities" (p. 25).

Narrative research engaged the researcher in two activities: "developing a well-founded story

that is faithful to life" and "drawing out the meaning, plot, or explanation embedded within [the] story" (Cochran, 1990, p. 78). The narrative analysis proper began with a close reading of the narratives. Initial thematic impressions were noted and significant events identified, with a descriptive term assigned to each. An example from the narrative accounts studied here would be the classification of one type of event as "gaining maturity". Even on the first reading of the narratives, this theme emerged clearly in all of the narratives and was universally described as meaningful to the experience studied; it thus became identified as a possible narrative theme.

Raw narrative data, of course, must be reduced to a form in which it can be analyzed. This study utilized the ethological approach, in which a selection is made from written narrative accounts, rather than the behavioural approach, in which the data is recorded at the time of observation, or the ecological or ethnographic approach, in which the classification of data starts in the field and is refined at a later time (Wilkinson, 2000). It also displays a content-focused orientation to the data, in which the researcher focuses on the referential and evaluative elements of the narrative rather than the structural or functional elements (Berman, 1995; Labov & Waletzky, 1967).

The narratives prepared for this study reflect as accurately as possible the stories shared by the participants. The researcher was not bound by any prescribed procedure in meeting this goal, but rather tried to ensure that the words on the page were capable of being confirmed as accurate and complete by the participants. The most reliable way of insuring accuracy is to strive for completeness; as Wilkinson (2000) says, "there is no 'correct' way or set pattern to writing up anecdotal reports, but they should always be as complete as possible" (p. 233).

Narrative themes emerged from listening, reading, and writing. The process of identifying themes was a long, slow, careful process, in order to ensure that the highest level of validity was obtained (Riessman, 1993). The process embraced both a systematic rereading of the transcripts and narratives, in which the researcher was immersed in the text, and a stepping-back period, in order to achieve some distance from the text. As Mishler (1991) has pointed out, analysis cannot really be distinguished from transcription; both are achieved simultaneously in a continuous

process of "testing, clarifying, and deepening" (p. 277).

As the narratives must be validated by the participants, the researcher tried to remain faithful to what actually happened in the interviews and to make the narratives as accessible as possible. Thus a concerted attempt was made to follow the tapes and transcribed interviews as closely as possible, editing only as it was necessary to preserve meaning and continuity, and to use plain, understandable language.

Without devaluing in any way the need to establish qualitative validity, it is important to state that historical truth is not the aim of narrative inquiry. Some might even say that narrative is essentially a dramaturgical or declamatory process, more suitable to the application of Burke's (1945) grammar of dramatism or Gee's (1991) linguistic analysis; perhaps narrative, after all, is too essentially one of Geertz's (1983) "blurred genres" to give itself up completely to the measured scrutiny of analysis. In the end, the narrative researcher must not be "enchanted by the myth that assiduous application of rigorous method will yield sound fact" (Gergen, 1985), and remember that trustworthiness and not truth is the ultimate goal.

The Narrative Case Study

Working within the qualitative and narrative domains as described above, the data sets for this study were gathered in the form of four narrative case studies. The case study approach is well-established as one of the preeminent research tools in human science; for this study the seminal works of Yin (1994) and Stake (1994) were used to guide the researcher. The case study method is ideal for studying interpersonal relationships such as those in this study; as Stake (1994) says, it seeks out emic meanings and lets each unique case "tell its own story" (p. 239). Indeed, Cochran (1990) has noted that "case study is probably the preferred approach to narrative construction" (p. 79).

Recruitment

Participants for this study were recruited using recruitment notices (Appendix A) placed with cancer facilities and organizations. Participants were screened over the telephone to establish suitability. A brief summary of the research goal, interview protocol, and informed consent procedure (Appendix B) was provided. Each potential participant was cautioned that reliving a traumatic experience can be upsetting. Questions were invited, a date set for the first interview, and assurance of confidentiality given.

The Interview Protocol

In arranging the interviews for this study, the researcher asked the participants to choose an interview environment in which they would be relaxed and comfortable. Two couples were interviewed in their homes, one couple in the husband's private office at work, and one couple in a private room at a restaurant. Each couple was interviewed as a dyad, since the focus of the research was on shared meaning. Although the participants were given a 1.5 to 3 hour range for the duration of the initial interview, the researcher allowed the participants to set the pace and determine the interview course. The four initial interviews lasted 2 hours and 40 minutes, 2 hours and 25 minutes, 3 hours and 20 minutes, and 2 hours and 5 minutes.

The interview protocol for the study was based on the semi-structured model of interviewing as developed by Smith (1995). Anchored in the phenomenological approach to psychology, it is predicated on the assumption that what a participant says in the interview has some ongoing significance and that there is a relationship between the content of the discourse and the person's psychological constructs. In other words, the researcher assumes a connection between content and meaning.

In determining the researcher's orientation during the interviews, the work of Kvale (1996) was used. In particular, the researcher strove to meet Kvale's ten quality criteria for the interviewer: knowledgeability, structuring, clarity, gentleness, sensitivity, openness, steering only to remain

focused, critical checking, remembering, and interpreting through extension of meaning.

Using the semi-structured interview framework, the researcher entered the interviews with a set of open-ended questions (Appendix C); these questions, however, were only representations of those areas of interest that the researcher wished to investigate. Questions were seen as invitations or prompts, designed to encourage storytelling and meaning-making. The interviewer was free to follow the participants as they explored their feeling and thoughts, and to respond naturally to those feelings and thoughts. Researcher involvement, however, was tempered by the realization that "the richness of the data is determined by the appreciation that the researcher has for the data" (Breakwell, 2000, p. 240).

Each interview was audiotaped and transcribed. Narratives were then prepared from the transcriptions. In a short second interview, each participant couple validated the accuracy and completeness of the narrative prepared from the first interview. Both the first and second interviews concluded with a short debriefing.

Although the goal in each research interview was to obtain meaningful data, the researcher felt it necessary to balance this effort with a consideration of the particular situation of the participants and the potential therein for emotional vulnerability and relived trauma. Keeping this ethical imperative in mind, the researcher took extra care to build rapport, protect from harm, and create an empathic environment. To that end, the researcher reviewed several sources on communicating with cancer-affected people (Barraclough, 1999; Blitzer et al, 1990; Houldin, 2000; Kleinman, 1988; Weisman, 1981) and drew upon an extensive amount of counselling and volunteer experience with cancer-affected individuals and their families.

CHAPTER IV

NARRATIVE ONE: BRAD AND ELLEN

Brad and Ellen had been married two years and four months when Ellen was diagnosed with breast cancer. Brad was 35 years old at the time and Ellen had just turned 36. Brad works as a mechanic and Ellen is a sales representative for an office supplies company.

Ellen told Brad about the diagnosis right after she got home from her appointment with the doctor. Although she blurted the news out to Brad as soon as he came home from work, she found it "very hard" to tell him. She couldn't bring herself to say the word "mastectomy", it sounded too final.

For Ellen the diagnosis itself was not as big a shock as the moment she had found the lump in her breast. She describes this moment as feeling "ice cold" and "frozen". In fact, when she first found the lump she was convinced it was cancer. She spent an agonizing week, not sleeping and not eating, mostly drinking a lot, telling Brad she was worried about work. When she received the diagnosis, she felt "lucky" that it was not an aggressive cancer and had not spread. In fact, she even celebrated this with her sister. But in spite of feeling fortunate in some ways, Ellen felt that "it's true, your whole world changes, turns upside down".

Brad was "bowled over" when he heard the diagnosis, as Ellen had told him nothing about the lump or the test. Brad also felt angry, although he wasn't sure at what. He was upset that Ellen had been keeping things from him until that moment. He couldn't really grasp it because it was "such a shock" and because he "had no idea what to expect".

For Ellen the question of how this was going to affect her work and her marriage was very important. Brad was also thinking about the effect on the marriage, but he thought the work issue wasn't important, that they had to focus on what needed to be done. Ellen thought that Brad was simplifying the issue, that he did not realize how important her job was to her.

Brad experienced a feeling of confusion about the cancer, feeling it was all a "big mystery".

He was very confused about what the diagnosis might mean in terms of physical changes to Ellen. It was overwhelming and momentarily he "felt like running away".

Both Brad and Ellen were shocked by the diagnosis because they felt they were leading healthy, active lifestyles. Ellen also found it hard to understand because her family is from "tough, hardy stock, hardly ever sick".

Brad and Ellen "drank a lot of wine" to help them cope with the diagnosis, but they also spent time talking about practical matters such as how to tell Ellen's family. That night as she lay in bed, Ellen started worrying about what the diagnosis might mean for the future of her marriage. She remembers that she longed for something from Brad, wasn't sure exactly what, but that he went to sleep. She lay there, "immobilized by fear" about what would happen to her and to her marriage.

For Ellen the entire treatment period was "very difficult". She had a lot of support from her two sisters, both in a practical sense and in keeping the atmosphere positive. Her father was quietly supportive as well. In addition, she met some other women with breast cancer and found it helpful to talk with them.

Both Brad and Ellen found it difficult to deal with the way that Ellen's mother was handling the diagnosis. Ellen describes her mother as "a bit hysterical...I wished she'd just go home". Brad says she was "a pain in the ass", that she approached it as a "death watch". Sometimes it was so bad Brad had to ask her to leave.

For Brad, the treatment period was a time of many challenges. He felt that things were out of his control, and this made him frustrated and angry. He got mad at people he had no reason to be mad at. He was extremely busy with his job and looking after household matters, including the care of many animals. He thought about how many people and animals depended on him.

During the treatment period Brad and Ellen felt a sense of separation from each other. They didn't talk much. Ellen perceived that Brad was "trying to be supportive", but felt isolated from him, felt that as a man he couldn't understand what she was going through. She often felt irritable at little things that Brad did. But even though she was feeling removed from Brad and was focused on

taking care of herself, she realized that Brad was "having a hard time dealing with everything".

Brad and Ellen both found that the effect of Ellen's surgery affected them deeply. Ellen became quite emotional when talking about it. Brad found the physical after-effect "shocking", and didn't know what he should say. He tried to put himself in Ellen's shoes to try to understand what she was going through. He tried to imagine what it would be like to have a body part cut off. In the end, however, he was certain that he "couldn't possibly understand".

Although it was extremely hard for both of them, both Brad and Ellen felt that it was something that had to be faced, and that it was better to be honest about it. Brad told Ellen how horrible he thought the after-effect of the surgery was. This type of honesty had always been a part of their relationship. Ellen found this a bit hard to deal with, but was grateful that Brad was dealing with it with the honesty that she had come to expect from him. In fact in some ways Brad just said out loud what Ellen was thinking.

Ellen found that Brad's honest reaction to things provided a balance to her sisters' constantly positive attitude. Unlike her sisters, Brad did not say "everything will go on just like before and it's not the end of the world". She was grateful that Brad "let it all hang out", because she needed both of these types of support.

Ellen felt a reasonable amount of confidence in her doctors, but she was "not impressed" with the way she was told about the diagnosis. She felt that she should have been told that she had cancer more honestly and directly, and that she should have received more opportunity to ask questions and more information.

For Brad, the cancer itself represented a loss of power and control. At first, it seemed to Brad that the cancer "had all the power", but then he and Ellen regained a sense of power when they refused to give in to fear.

Ellen saw it a bit differently. She says that she never felt any loss of control, that their experience with facing the cancer was "a separate thing". For her cancer was something that happened to somebody else. It seemed to her that everywhere around her people were talking about

cancer. Most of all, for Ellen cancer meant "the end of 'my former life'".

Both Brad and Ellen, however, felt that the word or idea of cancer had a lot of power in itself. They both described the cancer as if it was some type of menacing creature. Brad said it had them both "by the throat", that they had to "wrestle it to the ground". Ellen had to get over thinking it was a "scary monster".

Brad spoke fondly about the helpfulness of humour in getting through the difficult times. Ellen agreed, saying that Brad could always make her laugh. Ellen also spoke about the empathy of pets, how they can know when you are hurting and will offer whatever comfort they can provide.

Both Brad and Ellen emphasized that the support they got from Ellen's family was very important to them in getting through the treatment phase. Brad did not get along all that well at times with his in-laws, but he gives them a lot of credit for the support they provided.

Brad and Ellen both felt considerable anxiety about how the surgery would affect their sexual relationship. They had a mutually strong attraction to each other that included sexual chemistry but also was expressed in the fiery way that they often communicated.

Although Brad thought the physical effects of Ellen's surgery were "horrible", he assured Ellen, and himself, that it would heal. He felt that it was important to be honest about how he felt, but he was confused at the status of their sexual relationship and didn't really know how he should act. He believed that their attraction for each other could not be affected by the cancer, that it was still there. But even though he felt that way, he didn't know if, how, or when he should approach Ellen sexually.

Ellen was also worried about their sexual relationship. She had always been an equal sexual partner, with a strong and muscular body, but now she felt like an "alien" in her own body, tired, weak, and overly sensitive. She didn't want to be touched too much, but on the other hand she remembered how it used to be, and therefore felt "so mixed up". She felt that their sexual activity since the surgery "wasn't any good", "wasn't like before", was just a "pathetic exercise". It seemed like they were trying to be "like the ourselves from before", but it wasn't possible. She started

thinking that maybe Brad should find some other sexual partner.

Brad was unaware that Ellen felt these things. He was not expecting that their sexual relationship would be the same as before, but he thought things would get better.

Brad and Ellen say that there were two events which made a big difference in restoring their relationship to the way it had been before the cancer treatment. The first was Ellen's return to her job, which made her feel that maybe she had recovered from the cancer and the "nightmare" of it. Brad felt relieved that Ellen seemed to have regained her strength, not just physically but emotionally as well. She no longer appeared weak, and because of that he was able to stop being the "Rock of Gibraltar" all the time.

Although going back to work did help in Ellen's recovery, she was actually going through a period of great emotional turmoil. In fact, she thinks that "it was actually hitting me for the first time". She felt that everyone had been putting themselves out for so long to look after her, that she had better "show a good face to the outside world". To everyone else she presented herself as a "cancer survivor", but inside she was "spaced out...numb, depressed". She felt that she couldn't share her feelings with anyone, and took to drinking to help her cope.

Brad was unaware of Ellen's inner turmoil, and was just relieved that everything seemed back to normal. He thought that he had the "old Ellen" back. He thought that things were "getting back to normal".

The second event that was important in further restoring Brad and Ellen's relationship was a retreat that Ellen went on for people in recovery. When Ellen met people who were in worse straits than she was, she realized that she was "a very lucky woman" and was able to see things "in perspective". At the retreat she also kept a gratitude journal, which she found very helpful.

When she came back from the retreat Ellen embraced Brad. In that moment, standing with her arms around her husband, Ellen felt for the first time that she really was going to be OK, that her life could be OK even if it was not the same as before, and that her marriage could survive the cancer experience. It was an overwhelming feeling, a feeling of permission to feel hopeful again.

Brad and Ellen were both shocked that cancer had entered their lives at the point in time that it did. For both of them this shock was closely connected to their perception of themselves as young, health-conscious, active people. Ellen also thought of her and Brad's parents and how they were still relatively healthy, so it didn't seem right that someone in Ellen's generation should be the one with the life-threatening disease. She felt that it was also not right that now she would be the sick one, the one that her parents would have to look after and worry about.

Brad had another perception of how the cancer did not "fit in" with his life. He had anticipated that his marriage would have challenges; in fact, he had spoken earlier of some they had already faced. But he thought those challenges would be "the usual stuff", the normal growing pains any marriage experiences. Clearly cancer was not in this category, leaving Brad feeling "weird" about its appearance in his life at this time. And he felt angry that their healthy lifestyle had not protected them from disease.

Brad and Ellen describe many changes in their marriage that were brought about by, or related to, the cancer experience. One of those changes was a newfound sense of maturity, of being more grown-up than people of the same age. Brad says he feels "older" now, even though on the surface not much has changed. Ellen feels Brad has always been more mature than his friends, but that he has become even more mature.

Ellen also spoke about how her girlfriends seemed to change in their attitude towards her for a time, treating her as "the leader" when they were together, a change that made her uncomfortable and which she believes is connected to her status as a cancer survivor.

Brad and Ellen felt that their cancer experience set them apart from their circle of friends. Brad was astounded at the lack of tactfulness and sensitivity displayed by a friend who told a "boob joke" in a bar during Ellen's period of treatment. Brad and Ellen realize, however, that their friends had no way of understanding what they were going through.

Brad and Ellen find that they relate differently to each other now because of the changes in their perception about "strength" and "weakness". Both Brad and Ellen had always thought of

Ellen as a strong, independent person, but the cancer experience has both confirmed this and changed it in important ways. Ellen now feels that Brad's protectiveness of her contains an appreciation of her strength and is not motivated by some "macho guy" impulse. Brad is clearly admiring of how Ellen passed the "test" she was given, and was made aware of how much confidence he has in her strength. For both there seems to be a realization that a person is strong when that person can accept a certain challenge that may weaken them, even make them helpless, and yet retain faith in their own strength through it all.

Brad and Ellen report that there have been changes in their lifestyle that they attribute directly to their cancer experience. Their life now is "slowed-down", "streamlined", "not so complicated". They have learned to appreciate quiet times together. They look back on their former life with affection, but view it as just that: a completely separate time in their lives, when they were completely different people.

When Ellen was able to accept that her life was going to go on, she felt all her sexual confusion and tension drop off, like a "shadow" lifting. Her thankfulness at being alive and being with Brad allowed for the true restoration of their relationship. As Ellen says, this was by no means a foregone conclusion; in fact, she says "it could have gone either way". Both Brad and Ellen felt that they had no experience in dealing with something like cancer, that at times it appeared stronger than their marriage bond and capable of destroying it. But in the end, when the shadow was lifted from Ellen, the bond, that mutual "chemistry", was as strong as ever, and, as Ellen says, "we found our way back".

Brad and Ellen agree that, after the cancer experience, their marriage is "definitely stronger". Even though they felt alone at the time with their individual experiences of the cancer, they chose to remain connected at a crucial moment. They cannot fully describe the threat that cancer presents to a marriage, and say that only other couples who went through it would understand. But they can describe why the marriage is stronger now: they have learned how to remain strong and independent individuals and at the same time look out for themselves more as a couple than as

individuals.

Brad proudly characterizes their marriage after the cancer as "Super Couple", that they are really a unique couple because of the individual and combined strength that they can count on to be there when they need it. Ellen adds that this sets them apart from their friends because it gives them a "a stronger base" to their marriage that others don't have. Ellen also feels that their cancer experience is unique because it occurred when they were both so young.

Brad and Ellen envision their future as both more secure and less secure. As individuals and as a couple, they both feel more secure, more ready to meet any challenge that may come their way. But now they also appreciate that plans are capable of being waylaid at any moment by an intrusion like cancer. When they plan for their future, therefore, there is a sense that the plans have a heightened importance than they didn't have before. Ellen puts it this way: "It's more meaningful when we plan now, because we know how easily it all could change".

This awareness of the fragility of expectations has also affected Brad and Ellen's communication about financial matters. Before the cancer experience, this had been an area of completely different attitudes for them, with Brad wanting more disclosure and discussion and Ellen being uncomfortable with such openness. Ellen is no longer so threatened by openness in this area, as she has been able to disconnect it from her fear of being controlled by Brad. This has meant a shared commitment not just in terms of money but also to the marriage itself, and has cemented a sense of trust.

Brad and Ellen have many things to say about cancer as a learning experience. Ellen feels that she has a new perspective on how things like physical appearance, sexual attraction, and communicative "fireworks" are not "the biggest deal". She had previously felt that because these forces of attraction in her relationship with Brad were so strong, they must constitute most if not all of the marital bond. The cancer represented a threat to all those forces, and hence to the marriage itself.

When Brad and Ellen's marriage became focused on the cancer treatment, it was like all of

the attractive forces were altered or stilled by the experience. Ellen felt that she was "in the middle of this quiet". When she realized and accepted that the marriage had inevitably changed, Ellen "took that quiet thing and brought it along with me...into the next phase".

Entering this new phase was a gradual thing for Brad and Ellen. They were not conscious at the time that such a big change was taking place. When they begin to describe the new phase, Brad and Ellen find themselves looking back on two former phases in their life, their marriage before the cancer and during the cancer period.

Ellen uses terms like "energy", "conflict", "push-pull", "fight like cats and dogs", "fun", "passion", "excitement", "up and down", "arguing", "turmoil", and "stress" to describe what their marriage before the cancer was like. Ellen says she "liked our marriage before, it was great", but she often wondered if it was going to last. She also recognizes now, in a wistful but accepting kind of way, that "I guess it couldn't stay the same even if we'd wanted it to".

Brad was always very aware that things would change, and he was ready to accept whatever that might mean. The hard thing for him was that he didn't know what to expect, was "in the dark" a lot, couldn't understand what his wife was going through. But he saw the upcoming change as a kind of do-or-die challenge, a "sink or swim kind of thing", a personal test to see whether he could "be strong when I was up against something I couldn't do anything about".

In looking at the new phase of their life, Brad and Ellen once again relive their cancer experience. Perhaps because they now have a new togetherness, they describe the cancer experience mostly in terms of separation and isolation. Brad says that a person can have lots of support, but "in the end you're alone with it". Ellen remembers that she felt "very, very alone, very isolated". They didn't communicate much, and they didn't know what was happening with the other partner. But in Brad's trying so hard to maintain their normal pre-cancer routine, they both took comfort.

Ellen remembers a moment that for her symbolized their entering into the new phase. It was a simple, calm moment, just Brad coming in and asking if she wanted to go out for dinner to their favourite restaurant. For a moment Ellen didn't think about the cancer like she always had before,

and it was a wonderful, liberating feeling. Somehow in that moment her thoughts went instead to Brad, and her heart went out to him, recognizing how hard it must have been for him. As Ellen says, "for the first time I didn't feel like I was apart from him". Ellen feels that this was the real start of her recovery, which she feels is "still in the works".

Although Ellen's healing process started when she went back to work and went on the retreat, the quiet, ordinary experience described above was very important because it allowed Brad and Ellen to finally put the isolated part of the cancer experience behind them. Although Ellen had been aware of Brad throughout the cancer period, and was sometimes irritated or angry at him, she was not ready to appreciate his struggles, his loyalty, his sincerity, his day-to-day presence. It was like a window of gratitude opened for Ellen that day, through which she could see her husband with new eyes.

Brad remembers the evening too. He talks about how he always thought of Ellen as his wife, through it all, how he never wavered in this feeling, how confusing it was when she couldn't accept that, how he was so tired of being "the villain". He sums up his feelings this way: "she was my wife, in all that means".

Brad and Ellen look upon their marriage now as "calm" and "relaxed". They realize that they "could have lost everything". They remember the issues that almost tore them apart, like their disagreement about having children, as "so pointless now". They have a much greater understanding about the futility of trying to change each other. They have been through their own individual hells, and a shared hell, and survived. They are proud that they "did OK with it, learned from it", and came out of it stronger and with a new level of respect for each other.

When considering why the cancer experience happened to them, Brad and Ellen see the experience as a "test", that most people are tested by something and the cancer was their test. They don't feel that such a question can really be answered, that the important thing is that they "passed the test".

CHAPTER V

NARRATIVE TWO: GERRY AND LINDA

Gerry and Linda had been married five months at the time of Gerry's diagnosis with skin cancer. Gerry was 28 years old at the time and Linda was 30. Gerry was working as a truck driver and furniture mover and Linda as an office manager at a uniform manufacturing company.

Gerry had noticed before the wedding that a wart on his neck had grown in size, but had put off going to the doctor until after the wedding. A biopsy showed that the tissue was malignant. Gerry had surgery shortly afterwards.

When Gerry heard the word "cancer", it "freaked me out". Gerry's dad had had a malignant wart removed many years previously, but Gerry didn't think he was in any danger at such a young age. Gerry tried to put the diagnosis out of his mind so he wouldn't be "eaten up by" anxiety. He says now that it probably would have been easier to just worry.

Between the diagnosis and the surgery, Gerry worked some extra hours so he could build up a bit of money in the bank. He also saw the physical work as a good way to work off his frustrations. He says that he wasn't frustrated at anything in particular, just at the "annoyance" of needing surgery.

Linda wasn't too surprised at the cancer diagnosis. She says Gerry has a lot of warts and she's heard that people with a lot of warts often have skin cancer. She saw it as a "bit of a downer" because they had just been married and were looking forward to a camping and skiing honeymoon in a few months.

Gerry's surgery went well; in fact, Gerry was surprised at how quickly it went. However, his neck was very sore afterwards and he had to wear a bandage for quite a long time, and then a special cream. He says that the worst part of it was that he "missed wearing a tie so much, ha ha". Gerry's parents were very supportive, "very sweet".

Linda says the surgery was "no problem". She remembers that the only real effect of the

surgery was that Gerry had trouble moving his head. She missed putting her arm around his neck, as she often did when he was in his computer chair. During the weeks after the surgery, Linda continued working and was gone during the day. Gerry "fooled around" on the computer a lot. Linda felt that Gerry should have some time to recover, so she "didn't bother him much".

Gerry was "pretty tired" in the week after the surgery. During the day he would play a lot of computer games or just watch TV. He had arranged to take a month off, partly so his neck could heal and also to get their camper ready for the honeymoon. In the second week after the surgery, one or more of his high school buddies would usually come over and they would "smoke dope and drink beer". For Gerry it was "like being in high school again", and he was enjoying it.

More and more, Linda would come home from work and find Gerry "out of it". Sometimes his buddies would still be there. She didn't know these friends very well, and wondered why Gerry wasn't hanging out with his regular friends from work or softball. She would sometimes get angry at Gerry but felt bad about it because "after all, he'd just had cancer". She says Gerry and his buddies would turn the house into a "pig sty". She'd clean up the mess and try to remember that Gerry was going back to work soon. She tried to get Gerry to work on the camper but "he'd say he would and never do it".

Gerry isn't sure how it happened, but soon after the surgery he started smoking marijuana every day around lunch time. He was no longer in any physical pain, and he knew that he had promised Linda he would work on the camper, but he just couldn't get interested in anything. All he seemed to be interested in was "pot and beer". He amends that to add "oh, and food".

In the weeks after his surgery, Gerry became virtually inactive. From being a very active person, moving furniture around every day and working around the yard, he went to being a "total sloth". Often he'd order pizza or Italian food. He started getting a belly, and sometimes he didn't shower for days.

Linda didn't know what to do. She thought to herself "This isn't Gerry", but that maybe this was the after-effect of having cancer, maybe it was normal for people to go into a "bit of a

slump". She thought, "oh well, he'll be back at work soon and everything will go back to normal". And she thought, "we're still going on our honeymoon, so he'll have to get himself together for that".

As the time for going back to work got closer, Gerry got less and less interested in doing so. It wasn't that he didn't enjoy his job, because he did, very much. He really liked and respected his boss, thought he was "a really cool guy" and paid very well. But he just didn't want to go back to work. He thought to himself, "what should I do?, my boss is counting on me to come back, Linda is counting on me to go back, I have to go back". He just didn't understand why the thought filled him with dread.

Linda had no idea this was going on in Gerry's mind. She thought he was just going through a phase. She thought his high school buddies were a "bad influence" on Gerry, because most of them "weren't exactly go-getters". She says that Gerry was "kind of chubby" when she met him, so she knew he could get out of shape, but she thought he just needed to get back to work.

Gerry and Linda were "avoiding each other" during this time, even though they were physically together most mornings and evenings. Both of them felt that something was "off" but that it would right itself when Gerry went back to work. Linda didn't want to "push" Gerry too much because he had just been through a difficult experience. Besides, most of the time he was too "out of it" to talk to.

Gerry and Linda weren't really talking much during this time. They would normally have dinner together every night and talk, but that wasn't happening. They were also not having sex during this time. Linda says Gerry would often "pass out" on the couch early in the evening.

Three days before he was supposed to be back at work, Gerry called his boss and said he wasn't coming back. He didn't tell Linda. He had to get "really drunk" to tell his boss. He felt very bad about doing this to his boss, who was counting on his coming back. He was afraid if he didn't tell Linda, she'd find out secondhand. So, the next day, he got very drunk again and told her when she came home from work. Gerry remembers that Linda had brought home a bolt of discarded

uniform cloth that they could use for the camper cushions.

Linda was "shocked". She asked Gerry why he had made this decision. Linda says Gerry said "Fuck that stupid job, I can get another one". Gerry doesn't remember the conversation, but he remembers that Linda was "as mad as I'd ever seen her". She threw the bolt of cloth against the wall. They had a fight that lasted all evening.

Gerry and Linda say this was not their first disagreement, but it WAS their first big fight. Linda was shocked not just at Gerry's decision but also at how "nasty" he was. She says that he called her names, including "pushy bitch" and "money grubber". She couldn't believe it was actually Gerry, he was so angry and foul-mouthed. She realized he was stoned and drunk, but at the same time she thought there must be some "reality" about the way Gerry was acting. She questioned the reality of her marriage, wondering if it was all "a sham".

Gerry and Linda remember that the fight went on past midnight. For the first while it was mostly about Gerry's announcement that he wasn't going back to his job, but later it also involved all kinds of other things. Linda just "let fly" with all kinds of things that had been bothering her for years (Gerry and Linda had lived together for two years before being married).

Gerry doesn't remember anything about the fight. He wishes he could, because he says now it's only Linda's version of what happened that he has to go on. He doubts that her version is completely accurate, because she was so mad at him. He doesn't deny that he was angry, because he knows that he has a temper.

Linda says she "remembers what she remembers". She says maybe she doesn't remember it word for word, but that she remembers "for sure" how angry they both were. She was very surprised at the intensity and amount of their anger. She thought it was so "weird" that they had just been married and now they were "at each other's throats". She remembers thinking "Is this the real Gerry? I've never seen him like this".

Gerry and Linda describe the period after this fight as "a stalemate". They did not speak to each other much and Gerry slept on the couch or in the spare room. Gerry continued to stay at

home, smoke marijuana, drink beer, and eat. Linda went to work, came home, and cleaned up. This went on for about two or three months.

Gerry says that, looking back, he didn't deal well with the cancer diagnosis. In fact, he says, he didn't deal with it at all. He didn't want to face the fact that he had cancer, and from the moment of the diagnosis, he went into "denial mode". He hates the word "cancer", and he's always been afraid of getting it. He didn't want to think about it, "before, during, and after", and he did everything he could to avoid thinking about it.

Gerry feels that maybe his cancer was just a minor cancer, but it wasn't minor for him. He felt "stupid" because other people were having to cope with much more serious types of cancer and dealing with it much better. He felt like a "weenie" because it caused so much anxiety for him. He felt angry at Linda because she seemed to think it was no big deal, and even though he KNEW it was no big deal, he resented her attitude. He also resented her expectation that he would just "heal up and then start right in on" the camper.

Gerry feels that the whole process of denial put a huge burden on him. He is not sure whether the "sloth" phase was part of the denial, or whether it was an attempt to lessen the burden of the denial, or both. He realizes now that surrounding himself with his old high school buddies was a way of pushing Linda away and also protecting himself, because "we just talked about stupid stuff like sports and cars". He didn't want to see his regular friends.

Linda maintained her normal round of social activities at first, explaining that Gerry was "having a bad reaction to the cream". She felt very uncomfortable around her friends, not because of the lying but because "they treated me differently". She says her friends didn't want to hear anything about cancer, that "they acted like the word could give them cancer". She thought that they were "a bunch of idiots". Eventually she stopped going to social gatherings.

Gerry says that although he didn't realize it, from the moment he heard the word "cancer" he started doubting everything about his life. As the weeks went on he not only felt disinclined to go back to work, he also started looking at his marriage with different eyes. He wondered why he'd

gotten married, and why to Linda. He started thinking about his old girlfriend and wondered what she was doing. He thought about calling her up.

Linda was totally unaware of Gerry's feelings about cancer. She says he treated it like a "simple matter" of getting the surgery and letting it heal. She says Gerry tends to avoid "getting into the nitty gritty" about most things so she thought it was his normal way of coping. She tried to talk with him about how he felt about the diagnosis and whether he should avoid working outside so much but he was "not too terribly concerned". She thought he was doing OK until he started drinking and smoking marijuana every day.

After the big fight, Gerry and Linda remained in their "stalemate" phase for about two or three months. Gerry continued to stay at home, drinking and smoking pot; Linda continued to go to work. Then, they say, "it happened". An old friend of Gerry's from out of town, Mark, came to visit. Mark is described by Gerry as "a bud from school, about my age, no I guess a year younger, kind of a live wire, gift of gab, girls always went ape for him, a good guy, we used to hang out quite a bit". Mark stayed with Gerry and Linda, but was usually gone during the day. Linda wasn't sure about Mark and what his influence on Gerry might be, but she was glad that he seemed "really ambitious about his future".

One night, Mark asked Gerry why he and Linda seemed to be so "hostile" towards each other. Gerry said "I don't know, why don't you ask her?" Linda was in the kitchen at the time. Mark asked Linda to come into the living room. Eventually she did, remaining standing. Gerry says he asked, without looking at Linda, "Mark wants to know why we're so hostile". Linda just stood there, not knowing what to do or say. Something inside of her wanted to reach out to Gerry, because she heard something in his voice that "broke my heart". But she remembered all the things he'd said in the big fight and this kept her from doing so. Eventually she said something, but neither Gerry nor Linda remembers exactly what. What they do remember is that Mark invited Linda to sit down and she did, in a separate chair. They remember that Mark said "What's up with you guys?" and they both laughed.

After some hesitation, a conversation ensued. At first, Gerry and Linda felt "awkward" with just being in the same room together. Gerry had had one or two beers but had not smoked marijuana because Mark "wasn't into it, some sort of allergy to smoke". Gerry and Linda both remember that they felt awkward looking at each other, but at the same time it was a relief. Gerry also remembers thinking how "pretty" Linda looked. Linda remembers thinking how fat Gerry's face had gotten.

Gerry and Linda talked that evening about a lot of things. They realize now that having a third party there was somehow conducive to openness and honesty and at the same time helped them maintain a certain level of civility towards each other. Mark occasionally made a comment but mostly listened; eventually he left to go out with friends. Gerry and Linda were surprised that he "stuck around" as long as he did, listening to "all our dirty laundry".

Gerry and Linda talked a lot about Gerry's decision not to go back to work. Gerry realized as he talked about it that it was "very complicated". He had a hard time expressing his thoughts and emotions. For the first time he had had to explain everything that had happened, everything that he had experienced, because Mark didn't know anything about it. He thinks that that was useful because it "made me have to put it all out there". He also thinks it was useful that Mark wasn't a close, regular friend, because, being a bit removed, he was fairly neutral.

Gerry and Linda talked all about Gerry's feelings about his cancer. Gerry was surprised, and a little embarrassed, at how open he was about everything, especially in front of Mark. At times he had tears in his eyes. He says he went into a "meltdown".

Through talking, Gerry and Linda realized that they had had completely different and separate experiences of the cancer. Linda was hurt that Gerry had kept everything inside, kept everything from her, but she understood that Gerry didn't know what else to do. She says she went from at first taking it personally to seeing that it had nothing to do with her.

In talking about the cancer, Gerry acknowledged that he has always had a "phobia" about cancer. He has always lived in fear of getting cancer, from as young as he can remember. He had

never told anyone about it. All his life he thought every small ailment was the onset of cancer. He has had a recurring dream that he is wearing a red jacket or coat and walking into a barn, and he thinks it might be connected to his phobia.

Gerry talked about how he believes his not going back to work was a way of asserting some control at a time when he felt out of control. He also said that Linda always seemed so much in control, and part of that was wanting to control him. The cancer was very much connected to the control issue, in that it was something that he felt no control over and destroyed his own sense of control.

Gerry and Linda discussed the control issue and found that they had very different perspectives on the issue. Gerry had an ongoing sense of just barely managing to hold onto his own share of the control in the marriage, feeling that Linda exerted most of the control. Linda felt that Gerry had the most control because he had a job, savings, and a car when they met, and she did not, because they lived in the house that Gerry was renting when they met, and because they had close ties to Gerry's family and friends and not to Linda's, as Linda was from out of town.

Another issue that surfaced for Gerry was how the cancer made him feel about himself as a person. Gerry started feeling "weak" when he received the diagnosis, a constant fatigue that seemed both mental and physical. He didn't talk to his doctor or anyone else about it because he recognized the feeling as something he had often experienced in the past. Whenever he feels "low" about himself he gets very lethargic and has trouble accomplishing anything. In this instance, the cancer represented a blow to his ego because he felt so "stupid" about the way he couldn't control his fear.

After their long conversation, Gerry and Linda decided to go to counselling, with the idea that they wanted to "sort things out". They went for two sessions but did not find it useful. They feel that maybe it was too soon for any in-depth counselling because "we didn't even know what the problems might be". They continued to have regular talks, however, and say it was like "getting to know each other all over again".

Gerry and Linda are glad that the cancer occurred when it did, so soon after they'd been

married. They say it "liberated" their real feelings because it forced Gerry to confront some things and in turn that made them both look at issues they'd never even mentioned. There is a freedom in their communication now. They look back at "the big fight" and say it was the "dam bursting", the pivotal event that put so many raw feelings out there that they couldn't be ignored any longer.

Gerry and Linda feel that improved communication is the biggest change in their lives since the cancer experience. They worked through what they now call Gerry's "sloth period" by agreeing to give Gerry a few weeks to decide what he wanted to do and by Gerry going to a career counsellor. Gerry wrote a letter to his former boss explaining his actions and apologizing for quitting at such short notice. In the end Gerry went back to his old job.

Gerry says that talking about his phobia has also been a liberating act. He feels very relieved and now he and Linda laugh about it, calling him "Mr. Hypochondria". Gerry says he still feels foolish about it, but "so what". Linda says she thinks it's "kind of cute".

Gerry and Linda feel "more secure" about their marriage than before the cancer experience. They realize that they never really communicated before, in a truly adult way. Gerry says he still doesn't feel completely like an adult, but he supposes that he's "getting it together more now". Linda says that "yeah, he's still a big kid", but she says she "knew that going in". She keeps a close watch on Gerry's warts because she says he's not diligent enough about it.

Gerry and Linda say their level of trust has always been high, but it has increased because they went through a hard time and survived. Linda is proud of Gerry's honesty and says it has made her realize just how high their level of trust is. Gerry knows that Linda doesn't understand his fear, but it is enough that she tries. He says he can always count on Linda, in every way.

Gerry and Linda think their experience with cancer has had a "focusing" effect on them with regards to their plans for the future. They talk more seriously about it now, although they feel that they are still young enough that they can "just enjoy life" for awhile. Gerry is very happy back at his old job, and Linda continues to enjoy her job.

Gerry had a lot of fun with his high school buddies, and he has kept in touch, but he laughs

about how "interesting" the "old high school thing" seemed to him. He realizes it was just a way to "avoid things". Gerry and Linda say they feel a bit "awkward" around their regular friends, and think it may be because they "don't know how to deal with" someone so young having cancer. Gerry says he wishes Mark lived closer, because he "really seemed to have his shit together".

Gerry and Linda think they are "a pretty good match", but they say that the cancer experience showed them how their differences can be "a big obstacle" to staying connected with each other. One example of this is their completely different feelings about illness. Gerry, because of his fear of cancer, is prone to let illness "paralyze" him and bring his everyday routine to a standstill. Linda tends to "work through" any ailment, taking a "mind over matter" attitude. Gerry and Linda say they never had to confront these things before, in fact were unaware of most of them.

Gerry talks about how funny it is that of all the people he knows, he's the only "cancer hypochondriac" and yet he's the one that got cancer. He says it shows "God has a sense of humour". He recognizes that he has to "live with" the possibility of recurrence and being "the cancerphobia poster child", but now he can talk about it. He feels "almost like there's a big hand pointed at me like in Monty Python".

Gerry and Linda are still working through issues of power and control. Linda acknowledges that she tends to be "bossy" and "opinionated", and says she finds it hard to take off her "manager's hat" the minute she walks in the door. Linda also acknowledges that she is much more ambitious than Gerry. Gerry and Linda are trying to incorporate this difference into their marriage as an asset. Gerry tries to appreciate Linda's ambition as "the kick in the ass I probably need", and Linda tries to see Gerry's laid-back attitude as a way of keeping things in perspective.

Gerry and Linda feel more like equal partners now. They attribute this to seeing things "in a more mature way". They feel that the cancer experience showed how two people working at cross purposes can make the experience a negative one, that it can affect a couple on many levels. They never actually saw the cancer experience as a shared experience in the first place, so couldn't be real partners during that experience. Again, Gerry and Linda feel that working with the control issue

helped them feel more equal.

Gerry and Linda say that they haven't got the perfect marriage, but they're "getting there!" They think that in their 30s they will build on what they have learned in the last while. They look back on the cancer experience and the "sloth period" and smile, because, they say, it was the "real beginning" of their marriage.

Gerry and Linda don't know why the cancer experience happened to them, other than that Gerry may be prone to it because of heredity. They feel that bad things happen "because things happen, who knows why". They don't really think about it much, and they feel the reasons aren't important; what's important is "the stuff that comes out of it".

CHAPTER VI

NARRATIVE THREE: NED AND TERRI

Ned and Terri had been married just over two years at the time of Terri's diagnosis with metastatic breast cancer. At that time both Ned and Terri were 32 years old. Ned works as a private investigator and Terri is a teacher.

Terri says that her cancer diagnosis was an "enormous shock". She saw herself as young and healthy, and had always enjoyed excellent health throughout her life. At the time her life was "very hectic": she had started work at a different school, her mother had recently remarried, she was redecorating the upstairs bedrooms of her condo, and she had just started investigating fertility treatments. She remembers thinking that she didn't have time for this, that now she'd have to rearrange her whole life.

Ned remembers the cancer diagnosis as a "shock" also. He felt an enormous rush of feeling, like a blow to the chest, a combination of love, protectiveness, shock, and fear. Ned also felt like he had to protect Terry from the "bad atmosphere" in the doctor's office, which seemed very "cold" to both of them. Terri still remembers the look on Ned's face as one of "fierceness, like an animal about to charge". Ned says, "You mean a chicken about to shit".

Both Ned and Terri immediately thought of how the news of the cancer would have to put their fertility treatments on hold. They both remember a feeling of sadness about this, as they had been very excited about planning to have a family. They had even been planning the baby's room and picking out names, all before any pregnancy had happened.

Terri remembers that the whole world immediately looked different. Driving home in the car, she was thinking that the colours seemed so unusually bright, almost painfully so. As the initial shock wore off, she thought about what a "dynamo" of energy and activity she had always been and how the cancer might change that. She already felt like a burden, long before she was incapacitated in any way. She remembers that she couldn't remember anything that the doctor had said.

Ned remembers that he thought "OK, this is it. Here's the big test". He'd always felt that something would come along to test his strength, and here it was. He had the fleeting thought that "I could just run away". He joked with Terri that "Hey, you know I'm a boob man, why are you doing this to me?"

Terri's mom was at their condo when they got home, helping with the decorating chores. Terri thought "Should I tell her? When should I tell her?" She says that she felt guilty because her mom was so happy about her new marriage. She remembers that her mom was wearing a cute red-and-white striped pantsuit. The colours still seemed very bright everywhere.

When he got home Ned didn't know what to do with himself. He went outside and thought of working on the car, but he couldn't concentrate. He went back inside and went upstairs. Terri's mom hugged him and was crying so he knew Terri had broken the news.

Terri says that telling her mother was the hardest part of the day. She says she just blurted it out: "I have cancer!", like it was some exciting news. It sounded so strange and inappropriate in the half-decorated room. Terri and her mom hugged and cried. Terri's mom offered to move in but Terri said it was OK.

That evening, Ned and Terri went out to dinner. They were both "teary" and couldn't eat much. Ned remembers that he tried to make jokes; Terri remembers that she was so happy that Ned was trying to crack her up like he always did. Later, Ned and Terri made love and Terri remembers how different it felt, not knowing how exactly but feeling that her body was somehow different. Ned felt relieved that he could perform; he had thought that maybe his body would react differently in some way.

Ned and Terri vividly remember waking up the morning after the diagnosis. Ned says that he felt another rush of emotion, but this time it was mostly fear. He says it was like "I was facing it for the first time". He thought about Terri having to go through treatment for the cancer, and tears came to his eyes. He thought about how he'd dated so many girls that "couldn't hold a candle" to Terri. He thought about their crazy wedding in Vegas. He thought about the sex they'd had last

night, and felt weird because he was aroused. He lay there, hoping it wasn't really true about the cancer.

Terri remembers looking down at her breast, wondering how it could look so normal. She thought about how her decorating seemed so pointless now. She had a fleeting thought about running away, just taking their Vanagon and disappearing. She wondered how long it would take her to die if she didn't do anything about the cancer.

Ned and Terri made love again that morning. They both felt unusually passionate and connected, but they didn't speak. Terri remembers that Ned didn't touch her breasts, and she was hurt by this. Ned doesn't remember that he avoided Terri's breasts, but he says he remembers how beautiful they looked to him.

Terri went through the treatment quite easily compared to some of the other women she talked to. She says that she has always been a "bundle of energy", so she just looked at it as a "big project" that she had to finish. She kept a journal and encouraged others to write in it. She remembers the physical pain, and says that she often cried by herself in the bathroom, "but only a little". She says that she's the one others always look to as a source of fun and leadership, and she felt that she wanted to keep as much of that going as possible.

Ned found that Terri's treatment period was "not as hard as I expected", but he says that going to the hospital with Terri was hard because of the depressing atmosphere. He was amazed at how well Terri handled the whole thing, and he developed a new appreciation of her courage and strength. He realizes now that she made it look "a lot easier than it really was". He wishes she hadn't tried to be so strong, but he knows he would have done the same thing.

Ned and Terri believe they could not have gotten through the treatment period without three things: a lot of support from family and friends, a sense of humour, and "a lot of playing hide the salami" (Ned's words). They also tried to stick to their regular routine as much as possible. Ned was able to take advantage of some accumulated time off, and found that he enjoyed cooking, "but not housework!" They both made an effort to remain upbeat and cheerful, and brought home their

first pet, a schnauzer they named "Booby".

Both Ned and Terri saw the cancer as an enemy invading their territory. Ned felt like a warrior at times ("a dishpan warrior"), but he knew in his heart that it was Terri who was the real warrior.

Terri often felt weak and helpless against the enemy, but would put on a brave face. Both Ned and Terri were aware of how the other was trying so hard to be brave and optimistic and felt this was like a "secret code" between them. This also made each of them appreciate and love the other more than ever, although they did not talk about it at the time.

Being great fans of Seinfeld, Ned and Terri hosted a "Seinfeld party" to celebrate the end of Terri's treatment. Ned dressed as Kramer and Terri as Elaine. Everyone there had participated in making a tape that celebrated Terri's life. For Ned and Terri, though, the best part of the evening was when they went upstairs at the end of the party and had champagne together in bed.

Ned and Terri felt that after the treatment ended, it was like an anticlimax. They both went back to work, but they felt "out of sorts, disconnected". Ned started to resent and dislike his boss, and thought of quitting. Terri turned into a "bit of a tyrant" in the classroom, and was a much harder marker than before. Their basic routine continued as before, however, and they even took several short vacations. At times they had arguments about trivial things, usually about how much time to spend with the in-laws or who was responsible for some household task. Ned says that this period was short-lived; Terri says that it went on for a long time. Ned felt that it was "just us, adjusting to normal life". Terri felt that it showed the "classic post-traumatic stuff", that they were experiencing a normal let-down phase after the emotional intensity of the treatment period.

For both Ned and Terri, the above period was a learning experience that was actually more challenging than the cancer experience. They thought it would be such a relief to return to normal, but it just didn't happen that way. They would often "thank their lucky stars" that they were together and everything was all right, but they just didn't feel particularly happy or contented. Ned remembers that on one of their vacations, Terri went off by herself for hours without telling him,

which greatly upset Ned.

Throughout the cancer treatment period and the period described above, Ned and Terri maintained a very active sex life. They both attribute this to their strong "chemistry" and to their openness and sense of humour about the changes arising from the treatment. Ned says that after the surgery, he was amazed and relieved that he felt the same about Terri. He adds that there was even an added attraction, in that she exhibited a new shyness and reticence that Ned found immensely appealing. He says that although he was afraid that the sight of Terri's body after her surgery would repulse him, he was actually more curious than anything, and it did not affect his attraction to her. In fact, Ned and Terri describe their lovemaking during and after the treatment period as "on a different plane".

Ned and Terri found that in spite of their marital success with the cancer experience, others were not so successful in dealing with it. Terri's mother remained steadfastly supportive, and Ned's family gave emotional support whenever they could, but Terri's new stepfather was, in Terri's words, "a jackass about it". He seemed to have trouble dealing with Terri's illness and in fact has not visited Ned and Terri since the diagnosis. Terri feels angry about this and it has caused some friction in the family. Ned says that it makes him think less of Terri's stepfather, but that some people don't deal with illness very well.

Ned and Terri have a large circle of friends, and they found the different reactions to Terri's cancer interesting to observe. Most of Terri's female friends were extremely supportive, but a few "stayed away". Terri has no ill feeling towards those friends, because she knows that people are different and can only give what they are able to give. She also says that just knowing that she had a large group of friends who would still be there when she recovered, "ready to party", gave her a lift during her treatment.

Terri commented about the importance of pets in people's lives. She says that she wishes she had gotten Booby (their schnauzer) as soon as she was diagnosed, because having him around would have been a real comfort. She observes that pets seem to be able to "draw off your pain, or

whatever bad thing you're feeling". Ned says that Booby is such a comical-looking dog, it was great to have him around just to look at his "Bozo face".

For Ned and Terri, experiencing cancer so early in their marriage was "a shock". They say that they were really not prepared for such a "stumbling block", that although the cancer treatment period was not that long, it seemed to really have a braking effect on their forward momentum.

Ned and Terri felt that, before the cancer, things were really proceeding well for them, that they were full of energy and optimism, that they were always making plans for their future. Then, when the cancer happened, it felt like all that went away, and they were surprised by this. It seemed like the effect of the cancer was greater than it should have been. The treatment period had gone very well, their marriage was stronger than ever, and their life was pretty much back to normal, but somehow their former energy and optimism was not the same. In spite of their best efforts, they could not regain their former happy and positive outlook.

Ned and Terri feel that of all the effects of the cancer, this shift in mood has been the most difficult to deal with. They realize that they're not the same people, that things inevitably change after having cancer. They both feel that of all the people they know, they were probably the best equipped to handle what happened. But still, after all that is said, they miss the way they used to be, and feel a lingering sadness because they know they can never recapture that time in their lives.

In spite of all of the above, Ned and Terri are glad that the cancer happened before they had a family. They feel that it would have been a lot more difficult if they had had children, not just emotionally but in a practical sense. They also feel that they were better able to concentrate on Terri and her recovery without the responsibility of children. And they say that if it was difficult to tell family and friends, how difficult would it have been to explain it to children?

For both Ned and Terry, the cancer experience changed the way they view their jobs. Even after the post-cancer period of unsettledness, they found themselves feeling differently about both their jobs and work itself. Ned found that his unhappiness and dissatisfaction with his work centred on the way his boss treated him. In the past he had been able to "grin and bear it", but now

he was able to really face the situation and consider his options. Ned has decided that in two years he will either quit his job and start his own business, or go back to school. He realizes that the cancer experience was a catalyst for getting him to think seriously about job issues.

Terri has experienced a turnaround in the way she feels about teaching, and she attributes this to her experience with cancer. After the brief period in which she found herself acting like a "tyrant" in the classroom, she found herself enjoying her job more than she ever had before. She adds, however, that she is now able to put her job into a better perspective, in that she does not let herself get overloaded with work or miss breaks or take the office politics too seriously. She also says that she has more understanding and tolerance, both of her students and her co-workers.

For Ned and Terri, work has assumed a role of lesser importance in their lives. They feel that before the cancer, they were quite ambitious and job-oriented. Now, they go to work and put their time in, but it's not as much of a focus for them as it was before. They feel that this is a normal phase, and that they will gradually return to their former, more job-oriented, state, especially when they get back to their family plans.

Ned and Terri feel that they have changed a great deal from the experience they have been through, and yet remain basically the same people they always were. Ned explains that they think differently about life, but are the same people; he then amends this to say that he supposes they aren't the same people, really, if they think differently! He says "it's difficult to explain". He wonders if other people who have been through the cancer experience would know what he means.

Terri comments that she and Ned "have the same personality, you know, the same character", but that inside they have "more toughness". She says there are times, especially at work, when she feels that everyone around her is "so wimpy", so unable to deal with even the smallest obstacles, so concerned with petty details. She feels "so above it", that she can just "sail through" staff meetings, that she is much stronger than anyone else. Sometimes she worries that her ego is getting too big; sometimes she gets impatient with people because they "just don't get it". She feels like she knows the "secret of life" and nobody else does.

Ned and Terri appreciate everything about their lives more now. Even the littlest things are more meaningful. Ned takes long walks with Booby the dog and just enjoys the outdoors, whereas before he was always "doing something", working on the car, gardening, building, playing sports, jogging, and so on. He has learned to appreciate "just doing nothing". He says that there is a part of him that feels he's not doing enough as a breadwinner, that he should probably pay more attention to getting ahead, but he feels confident that his ambition will return.

Terri talks about how conscious she has become of her health. She says that she and Ned were always active, but that they took their health for granted and didn't pay too much attention to their diet. She feels more connected to her body and is much more aware of what she puts in it. She thinks that this is a very positive change in her life. She has also gotten interested in tai chi and yoga.

Terri does not think much about how her body has changed. She is grateful to Ned for the way he dealt with her physical changes. She has gotten used to wearing a prosthesis and has even given it a name. She says she never had large breasts anyway so she hasn't got much to miss. She notes that many people lose a body part such as an arm or leg, so it could be so much worse.

Ned and Terri's relationship has "changed for the better". The most important changes have been an increase in communication and a decrease in what they call "sniping and bickering". They remember that they used to constantly take "little jabs" at each other. They feel that this was all about "control", that they both wanted the upper hand. They also say that they were having "in-law problems" all the time, and that that caused a lot of their arguing.

Ned and Terri both feel that they paid too much attention in the past to their in-laws and not enough to themselves. They both felt a lot of pressure from their in-laws and they took their frustrations out on each other. They felt that they were expected to help out a lot with Terri's mother's wedding and honeymoon, even when they were very busy themselves, but they felt they just couldn't say no. They were also helping out financially, and this was another source of tension.

Since the cancer experience, Ned and Terri are spending much more time alone together,

rediscovering their identity as a couple. They have not seen nearly as much of either their in-laws or their friends. They say that this felt odd at first, because usually they "had plans" and now they often didn't. They sometimes felt guilty because they knew that their family or friends had asked them to help out with something or go out somewhere, and they were "just sitting at home eating and watching TV". Terri says Ned was better at refusing invitations than she was; she says she has a "big-time helper, go-along thing" going. Ned says he was doing it to protect Terri at first, but now he sees that it was good for both of them.

Ned and Terri sometimes miss all the good times they had with their friends, but at the same time they feel they "aren't missing anything". They don't feel the same around their friends now. They're able to have good times still, but not in the same way. They feel a sense of distance, even though they have remained close to all of their friends. They feel as if their friends treat them differently, that they are "bending over backwards" to be caring and nice, but it feels overly nice. Ned says this is especially true about his guy friends, who don't "razz" or "insult" him like they used to. Ned also feels uncomfortable about the way his friends talk about women and enjoy pornography. Terri doesn't feel like a sick person, but she says her girlfriends never fail to inquire about her health "in a hushed tone of voice". Both Ned and Terri feel that, even more than before, they are looked to as leaders of their social crowd, but now they don't enjoy it like they used to.

Ned and Terri joke that they have always felt that their relationship is unique, so nothing has really changed! Ned says "Can we be MORE unique? Can we be EXTREME unique?" They say that they're not different because they've gone through cancer, that many couples go through cancer, even at their young age. No, they say, they're different and unique because of the way they accepted the cancer as part of their life. They never let themselves live in denial, give themselves up to depression, or take their worries out on each other. From right after the diagnosis, they "just automatically" went into "deal-with-it mode". They credit their family backgrounds and their jobs for this. They realize from meeting other cancer patients that other people do not handle things as well.

Ned and Terri think more about the present now than the future. They think they need a period of time where they don't have to be completely serious and focused about the future. They try not to feel guilty about this. They feel that they are still doing better financially than a lot of their friends. They are still thinking about having a family, but this is not as much of a priority right now.

Ned and Terri have a sense of relief that they got through the cancer experience so well, and this makes them confident that in the future they will be able to meet any crisis that life may present to them. They look forward, in fact, to more challenges. They feel that they know they can handle "pretty much anything".

Terri says it is sometimes hard to maintain her sense of having recovered in the face of her mother's and other family members' "gloom and doom". She says that they think a cancer diagnosis means you are never really cured, that there's always a chance the cancer will return. Terri says she has learned to "turn a deaf ear" to these sentiments. She says it's "either one or the other": people either put so much pressure on you to "be recovered, be all glad you're not dead", or "treat you like it's only a matter of time before it comes back". She says her definition of recovery is "keeping yourself centred", and thinks she is in an ongoing process of "letting my inner child" be "scared but still OK".

Terri doesn't take the future for granted anymore. She wants to get as much out of life as possible. She thinks it was somehow "fate" that she got cancer. About a month before the diagnosis she had a strange dream in which she was on a beach, playing in the sand. The sand had pieces of broken glass in it and she cut her hands. She believes that this was an omen about her breast cancer. She feels "strange" about saying it, but she feels like the cancer experience was somehow "sent" to her. She says she has no feeling of anger or unfairness, and sometimes she thinks this is "kind of weird". Many people, hearing of her diagnosis, suggested that she pray or go to church. Terri feels that she has her own sense of spirituality.

Ned and Terri feel that their marriage is the most secure one that they know of. They are

"turned off" by the arguing and bad feeling that they see in many of their friends' marriages. They have trouble listening to their friends' "trivial" disagreements. They feel that most couples don't realize how lucky they are to have each other. They feel that most people expect too much, and are unwilling to compromise. They observe that a lot of their friends continually find blame with their partners, not wanting to take any responsibility themselves.

Ned and Terri feel so much more "grown up" than a lot of other people their own age. Ned says that sometimes, in the middle of a party or night out with their friends, he feels like "a much older guy" than the other men there. In fact, he feels that they are still enjoying being BOYS, even though they are in their 30s and married. For Terri, it is not a new experience to feel more grown up than those around her, because she has always felt that way. She says she is what people mean when they call someone an "old soul".

For Ned and Terri, cancer has been many things in their life. At first, cancer appeared to them to be an "invader", a threat, something to be fought. Terri says that one part of this attitude had to be maintained throughout the treatment, to keep up their resolve and courage. Ned often wished he could have physically attacked the cancer. The cancer was also like an "unwelcome visitor", in that Ned and Terri knew that they "had to live with it" but wished it would just go away.

The cancer experience has been very meaningful to Ned and Terri as a couple. They do not wish cancer on anyone, but they feel it can bring out the best in a marriage if the marriage is a good one to begin with. Ned feels that cancer is "a pretty damn good litmus test" of a marriage. As a couple they felt like they had been on a "long trek" or "mission" to see whether they had what it takes to survive. Ned jokes that he could have done without this challenge, because "I like puzzles, but I've always done badly on tests".

Terri feels that the test metaphor is quite relevant to her because she is a teacher. She is usually in the position of giving tests, rather than taking them. She says that if cancer is a test, it is a test of "an awful lot of things". She feels that cancer tests you physically, mentally, and emotionally. She wonders who decides "who has to write the test". She describes the test of cancer

as not about "you versus the disease", but rather "you versus you". She explains this by saying that the cancer and all the "bad forces" are working to defeat you: fear, confusion, fatigue, pain, depression, pessimism. All you have against this is what you can "bring to it yourself": family, friends, love, support, a positive attitude. Terri jokes that she would have had "test anxiety" if she'd viewed the cancer as a test from the beginning.

Ned and Terri believe that the most meaningful thing to come out of the cancer journey is their new experience of the word "love". This was never more clear to them than on their last wedding anniversary. They felt an overwhelming feeling of gratitude surrounding their celebration, gratitude that they had found each other in the first place, gratitude that they had shared the cancer experience together, and gratitude that they were both so healthy and happy.

Ned and Terri are not sure why the cancer experience happened to them. They do not think that questioning what "fate" has brought them will do any good. They feel that this was their "big test" and that now they can "get on with life".

CHAPTER VII

NARRATIVE FOUR: ROB AND SUSAN

Rob and Susan had been married three years at the time of Susan's diagnosis with uterine cancer; Rob was then 29 years old and Susan 33. Rob works as a fire inspector and has his own bookkeeping business; Susan is an X-ray technician.

Rob and Susan describe their marriage before the cancer diagnosis as "stressful" and "tense". The major factors contributing to this description have been a sense of dissatisfaction with the other's personality and actions, a lack of trust on Susan's part that Rob has been faithful to her, and a frustration on both parts that their incomes did not meet their needs.

Susan was "completely shocked" at the cancer diagnosis: there had been no history of cancer in her immediate family. She remembers that her initial shock quickly turned to anger, an anger which has not abated to this day. Susan is unsure of why she feels such intense and lasting anger, but feels that it is connected to her disappointment and hurt with the way her husband dealt with her diagnosis, treatment, and recovery.

Rob did not know how to react to the diagnosis. He says it was "quite a shock", like being "hit in the stomach", but that he never considered leaving Susan. He wished that they weren't in the situation they were in, but he just "tried to deal with it". He worked long hours, started working out with weights regularly, got together with his buddies a lot, and "probably drank too much".

Susan states that her husband did not comfort her when she received the devastating news that she had cancer and in fact was inattentive and cruel. She remembers that he said that maybe she "spent too much time riding horses" as a child, and laughed as he said it. She also remembers that he seemed to resent taking her to the hospital and having to perform many household tasks himself. She also does not remember much kindness in the way of looking after her or making her feel that he was there for her.

Rob acknowledges that he was not the most attentive husband at this time. He says that he is not very good at "that hospital thing", and refers back to his mother's long battle with heart disease, in which she was in and out of the hospital for many years. Rob says that Susan had a lot of other support during this time and that he felt he had to keep things going at home, at his job, and in his business. He says that he did not resent any of the extra work, feeling that it was his contribution to things. He says Susan was aware of how he felt about hospitals, and should not have expected him to "do something I'm no good at".

Susan feels hurt and angry that Rob did not take a leave of absence during the time she received treatment. She says that there was nothing preventing him from doing so and that in fact he had been talking about doing so.

Rob was worried about their financial situation and did not want to jeopardize that; in fact, he says that he immediately started working extra hours in his home business so that more money would be coming in. He didn't know how long Susan would have to be away from work, so he thought he'd better "get us prepared financially". He says that Susan knew when she married him that he was very "work-driven", and that he only wanted to protect their financial future. Rob also says that the only reason that he and Susan have such a nice house and nice stuff is that he "burns the midnight oil".

Susan did have a lot of support from friends and family, but she says that did not mean she didn't need or want Rob's support. Susan describes several instances in which she asked Rob for comfort and support and he was "not interested". Susan notes that since she was staying in a separate bedroom during this time, it was even more important to her to have regular contact with Rob. She says that sometimes she not only did not have regular contact with him, she did not even see him for days. She says that at other times she heard him moving around downstairs, but that he would rarely come to her room. Susan was quite weak at this time and was under doctor's orders to rest, but she was disinclined to come out of her room anyway because of her fear that she would just be hurt by Rob's indifference.

Rob says he was very busy and wanted to make sure that Susan was not disturbed and could get plenty of rest. He says that he is not a "sickbed kind of guy", that Susan knows that, and that Susan should have known he was trying to support her in his own way. Rob says that he felt funny about going into the "sickroom" and was not sure of what he could have said or done. He says he does not remember Susan reaching out for support, that usually she was "surrounded with people looking after her". He felt that during much of this time "Susan wasn't really Susan anyway" and he did not know how to adapt to this situation. Rob explains this by referring to Susan's anger, which seemed so intense he didn't know how to cope with it.

Susan says that although her anger may have intensified during this time, there had been lots of anger between them before the diagnosis; in fact, she says, their anger with each other had many times led to talk of counselling. Susan remembers thinking at the time of her diagnosis that Rob might use the diagnosis as an excuse to "take off". Susan feels that she wasn't able to count on Rob when it really mattered, and that all her doubts about him were confirmed by the cancer experience. She talks about a time when she wanted to get a cat and Rob wouldn't agree to it. She feels that it was such a simple thing but that Rob wanted to deliberately thwart her. She also says that he never put any thought into her Christmas and birthday presents.

Rob doesn't remember being against the idea of getting a cat. He says he likes dogs better, but that Susan was free to do what she wanted. He says that he's never denied Susan anything. He says that he knows he's "not much of a romantic", but that he surprised Susan twice with trips to Hawaii and the Caribbean. He says "I do what I can".

Susan experienced her cancer treatment as "an alone time", even though she was surrounded by support. She felt no confidence in her doctors, but she "just went along" with what they advised. She felt helpless even though she knows she wasn't, that many resources were available to her. She recalls feeling so angry that it "paralyzed" her. She characterizes herself as a smart, independent, competent person, but she could not seem to take control of what was happening to her.

For Rob, Susan's treatment period went by "like a blur". He was not aware of exactly what was happening to Susan, and he says that he probably shut it out deliberately. He remembers that Susan's mother and sister were at the house a lot and that that made him feel that things were under control.

Susan was told that her treatment would result in her not being able to have children. Susan remembers being numb at first and then feeling more anger. She says she felt that it was enough to go through cancer, why did this have to happen too. She and Rob had talked about having children "sometime in the future, maybe two or three years". She had always wanted kids because she came from "such a happy family", but her marriage hadn't ever seemed strong enough to bring kids into it.

Rob has always wanted kids and felt that he was ready for them "anytime". When he heard that Susan had uterine cancer, it "hit me" that maybe "I'd never be a father". He kept his thoughts to himself but was privately very upset about this aspect of the situation. He thought about adoption for the first time, but was not enamored of the idea. He was angry that the doctors seemed so certain about the outcome. He felt that he didn't know whether he really trusted their judgement, and was annoyed that Susan seemed to accept her cancer treatment without question.

Susan felt like her body was "a stranger" to her. She had always been slim, but she lost even more weight and looked "pale and ghostly". She found living in her body difficult. She would dream that she was bleeding profusely. She was given anti-depressants but did not find them helpful.

Rob did not think of Susan's physical body during this time. He says that he's "squeamish" about such things. He realizes that he probably didn't want to face the fact that Susan might be "different".

Susan had never thought about the possibility of getting cancer. Her family has had very few health problems, and they have always been an active, health-conscious family. She felt

"uncomfortable", in fact, about telling them about the cancer, feeling that she had somehow let them down. She was always the most athletic person in the family, and had won many prizes in equestrian events. She knew that her family would support her, but was worried about the pain it would cause them. She thought her 30s would be "a great time, my mother said it was the best time in her life".

Rob knows a lot about "what illness can do to a family". He doesn't like that sickness can have such power over people. He saw Susan's cancer in this light, as a threatening force that would bring unwanted change to his life.

Susan saw her cancer as an "intruder" in her life. She felt great anger at the cancer, or at least at what it was doing to her. She remembers that she had a vague image of the cancer as a "green blob, moving around like Jello". She never thought directly about it, but always indirectly, and in this way she protected herself from "going crazy".

Rob says he can't imagine what it's like to be told you have cancer. To him cancer is very powerful, not just the disease but the very thought of it. He always tried to avoid thinking about the cancer itself.

When Susan was too overwhelmed with things, she would meditate. She says that sometimes she could and sometimes she couldn't. She also thought about where she was going in life, "were things good or bad or what". She notes that she went to a counsellor briefly but that it didn't seem to help her, she just "got angry" at the counsellor. She felt very grateful for the support of her family, from the daily visits of her mother and sister to the "back-up strength" of her father. She didn't eat much, because food was not appealing to her. She remembers the first time she put on "one of my regular outfits", a flowered blouse and beige skirt, and that she thought she looked "skinny but nice". She was surprised at her interest in her looks. She says that in a way, maybe her anger helped get her through things, too: "I just blasted my way through the hospital stuff".

Robin and Susan felt that the cancer diagnosis did not feel like it occurred early in their

marriage. They cite their three years of marriage and a long period of knowing each other previous to the marriage as the reason for this. On the other hand, they think that the cancer occurred before they'd had a chance to work out their problems, so in a sense they had a "new" marriage. They feel that since their marriage has been "eventful", they have more "married life" behind them than most couples in their situation.

Rob feels that the experience of Susan's cancer has made him "tougher". It really made him appreciate that a person can be dealt a surprise blow at any time. He now feels better prepared for "what life throws at you".

Susan feels that although her body has changed, the most profound change has been in how she thinks about life. She feels that now that something so terrible has happened to her, she's not concerned about the minor things in life. All of her concerns about getting ahead seem trivial now. She will never look at a child again without feeling a sense of loss and pain. She believes that she has changed in some deep way that she cannot really explain.

Rob is working harder than ever. He feels that he's even more driven now than before. He doesn't think of this as a change, but rather as a response to a "wake-up call". He likes to think that he can rise to any occasion and come out of it "on top". He hopes that all his hard work will "pay off". He says he has no time these days for social activities, and anyway he feels like he doesn't really "fit in" with his friends anymore.

Susan feels that Rob is too concerned with being "the tough, macho business guy". She no longer looks at Rob as her protector, she realizes now that she is her own protector. She believes that women are "tougher than men anyway". She says she has no patience with most men, "they just don't get it". She has revived an interest in feminist literature, and feels most comfortable around "my women friends who get it". She says that she feels both stronger and weaker now. She can't imagine anything she can't handle, but she also feels quite "weepy" most of the time.

Rob and Susan both say that their marriage is no stronger, but also no weaker, than it was

before the cancer experience. Rob is "just taking it day by day". Susan is "still recovering" from the cancer. Their marriage is therefore in a "state of flux", and they are unsure exactly where they stand as a married couple. In fact, they don't really feel like a married couple. They see friends and do things separately. They feel apart, but feel the marriage vows "still mean something". They can't see how to fix things, but think "anything's possible".

Rob has been thinking a lot about the children issue. He feels that adoption is on his mind a lot more now, but that he's "not sure" about it. He doesn't know why he and Susan haven't talked about this issue, he says he would like to.

Susan feels that the more energy she gives to the "whole marriage thing", the less she has left for herself. She feels that she should not have to think about children right now, that it is too painful. She says maybe she should be recovered by now, but "it's like I'm just starting".

Rob and Susan feel that they have always had problems communicating, and that the cancer experience has made this even more true. Rob doesn't know exactly why this is so, but that it probably has to do with "trust". He feels that Susan doesn't trust him and never has. He says that he's been aware "since day one" that he and Susan would have "mega conflict", but that he liked "that sort of thing" between him and a woman. He remembers that on their first date he and Susan had a "huge argument", but that it "got the juices flowing". He also remembers that on that date Susan said she liked the way he "kept her guessing". He's not sure if his marriage is "just normal, or wacko".

Susan says that she knows what a marriage is "supposed to be like" because of her parents' marriage. She says her own marriage has been very different. She says that from the time she started dating Rob, she "didn't really trust him". She says he is "very charming, very macho", that he "flirts a lot", and that "women go for it". She is certain he has been unfaithful, but she has tried to ignore it. In spite of this, she has always found Rob "very attractive", and the cancer experience has not changed that, "but yet it has".

Rob feels that there is nothing he can do or say that will change the situation. He likes that

he and Susan have always had "that spark". He says he still loves Susan, but that sexual relations "seem to be in the past". He doesn't know why this is so, but feels that Susan knows and hasn't told him. He says that he expected her to return to the marital bedroom after a period of time, but that she hasn't done so. He says she has no reason not to trust him.

Susan feels that she is not ready for "the marriage thing". She feels angry that Rob seems to "expect something". She believes that Rob has been recently unfaithful. She wonders how much longer she can put up with her feelings about this. She says she "has no proof", that after all she "was so weak I could hardly get out of bed". She feels that her room is her "sanctuary", and feels "kind of like a prisoner, but a very safe prisoner". She says she needs time to think.

Rob says he doesn't expect anything from Susan. He feels that he has been very patient. He is willing to be patient "as long as I need to be". He feels that there has been a lot of pressure on him from Susan's family. He does not know exactly what is expected of him, and nothing has been actually said, but Rob feels a "constant pressure". He has no idea about what might happen in the future, so he just keeps to his "usual routine". He realizes that Susan wanted "more attention" during her treatment period, but now she "doesn't seem very interested in any attention". He feels that there is a "wall" between them.

Susan says she is "too angry" to deal with Rob right now. She feels that things get a little easier day by day and in the future she can imagine sorting things out, but not right now. She says "anyone would be angry" after what she's been through. She says "I need to do this in my own way".

Rob and Susan both feel that the cancer experience has had a deep and lasting effect on their marriage. They are not sure how much of this is a direct result of the cancer experience and how much relates to the state of their marriage prior to the cancer diagnosis. They would both like to arrive at a more comfortable, contented place, but as of yet they are unsure about how to do this and what it will involve. They intend to see a counsellor through the cancer clinic where Susan received her treatment. They say they both still love each other.

Rob and Susan have "no idea" why the cancer experience happened to them. Susan has thought about it a lot but hasn't come up with anything. Rob feels that Susan needs to work this out because she's obviously very angry about getting cancer. Rob and Susan say they expect that they will have to deal with this issue in counselling.

Chapter VIII

NARRATIVE ANALYSIS

After the narratives were validated by the participants, they were analyzed by the researcher to elicit narrative themes and the meanings revealed in them. Each theme is organized under a triad of names in order to best capture the complexity of the cancer experience. Some of the meanings are explicit in the narrative, whereas others are implicit. Some of the themes reflect the commonality and universality of the cancer experience, whereas others embrace meanings that are unique to young married couples.

The validation of narrative themes was an ongoing process. Trustworthiness, not truth, was the aim: the latter presumes the existence of an objective reality, while the former celebrates the shifting, subjective realities expressed in stories. Narratives are products of an interpretive process; remembered experience is a selective reconstruction. Trustworthy narratives capture the selection as offered in the particular moment.

Although a variety of sources were used to test the narrative themes for qualitative validity, the final check was made against Riessman's (1993) four criteria. First, the narrative themes presented in this analysis are persuasive: they are plausible accounts of transcribed experience. They reflect meanings contained in actual conversations. They contain subjective personal truths despite the limitations of rhetorical writing.

Second, the narrative themes show correspondence between the interpretations found in the raw data and the interpretations made in the narrativization process. The work was taken back to the participants to engage them in the validation process and ensure the highest level of correspondence. In this way credibility is established for narrative themes that are embedded in verified narratives.

Third, the narrative themes show coherence of interpretation. There is a global coherence, in that the themes relate to the overall goal of the narrators to communicate meaning. There is a local

coherence, in that the themes are intrinsically connected to the stories told. And there is a themal coherence, in that the themes represent recurrent strands of meaning expressed explicitly or implicitly in the narratives.

Fourth, the narrative themes have pragmatic use, in that they provide research interpretations that others can test against the empirical data of the narratives. In addition, the researcher offers the research work with the practical understanding that methodology and interpretation bear the imprint of the researcher's assumptions and values.

The results of this analysis were verified by an independent reviewer.

Schematic Representation Of Narrative Themes

In conceptualizing how narrative themes might relate to the cancer experience as a lived process with some structural integrity, various models were considered. Linear models did not capture the ebb and flow of the experience; cyclical and spiral models did not represent the subtle but discernible movement through domains of meaning. The researcher struggled to achieve a conceptualization that could encompass both temporally-linked impact stages and diffuse, shifting emotions and experiences. Such a model would capture the cancer experience as a dynamic, ongoing process that nevertheless contained discrete, recognizable challenges or themes throughout its course. These themes would appear in the model as a complex, interrelated series of meaning-making experiences that in their unique entirety would define the particular cancer experience of each individual or couple. In so doing, the model would also reframe the concept of recovery as an intricate, fluid, ongoing process that is inextricably linked to the existential choices made in the face of each meaning-making challenge. The model would also need to be compatible with the narrative approach and thus capable of representing the natural progression and climactic nature of storied experience.

After much deliberation, an arcuate, or arc-shaped, model was chosen to represent the narrative tension of the shared cancer experience. Within the model, three domains of experience

are identified: Initial Impact, Marital Cohesion, and Resolution and Gain. The domains are not meant to represent temporal phases, but rather clusters of meaning-making opportunities grouped according to processual needs and challenges. Each domain consists of five themes representing the meaning-making challenges that universally defined the cancer experience for the participant couples and thus became an integral part of their shared narratives. Although the participants moved back and forth through the themes in a non-linear, dynamic manner, there was a certain alignment between domain and process.

The first domain, Initial Impact, arises out of the cancer diagnosis and encompasses themes of shock, disorientation, invasion, isolation, and dissonance. Shock, disorientation, and invasion are immediate and often visceral reactions to the diagnosis, and are generally resolved relatively quickly in order that a sense of marital congruity and coherence can be maintained. In the case of isolation and dissonance, an ongoing application is evident, and in fact these two profound existential challenges had not been fully resolved by any of the participants.

The second domain, Marital Cohesion, consists of themes of collaboration, devotion, hope, connectedness, and humour, and represents concepts that are central to marital cohesion. These themes are situated at the bow of the arc, at the point at which it could “bend or break”, to symbolize their crucial role in shared meaning-making through the main body of the experience. It is thought that the presence of these themes within the marital narrative allowed the tension of the cancer story to reach a certain climactic point without breaking under the pressure of the experience’s traumatic effects.

The third domain, Resolution and Gain, embraces themes of acceptance, creativity, pride, maturity, and control. This domain reflects themes that, while present throughout the experience, were aligned with the successful negotiation and resolution of the meaning-making challenges presented by the cancer experience and the marital gains that arose out of this shared journey.

Figure 1 illustrates the above conceptualization of the cancer experience:

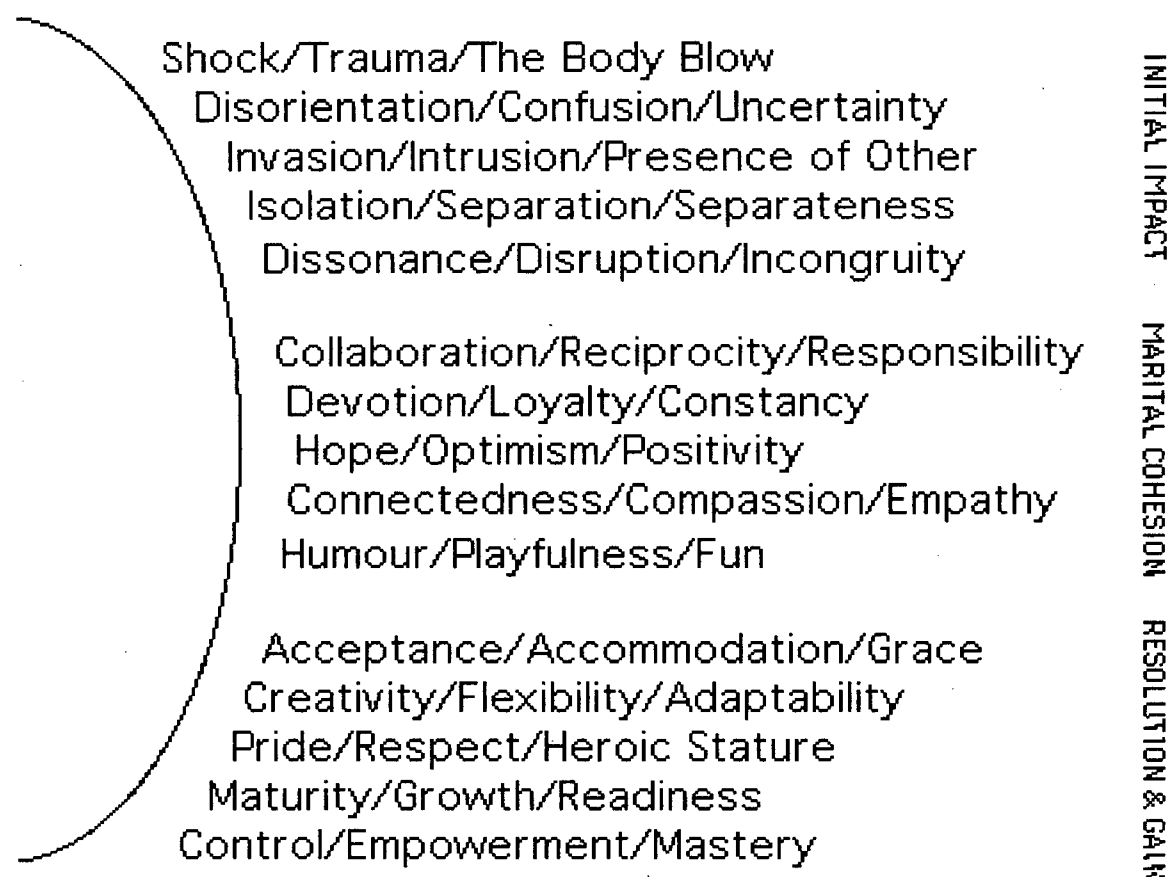


Figure 1: Arcuate Model of the Cancer Experience

The Cancer Experience: Domains and Themes of Meaning

The following discussion describes the fifteen themes, each represented by a triad of names, that make up the three domains of the cancer experience.

Domain One: Initial Impact

Shock/Trauma/The Body Blow

The word "shock" runs through all of the narratives. Ultimately, after the initial emotional trauma is accounted for, shock aligns itself to a disruption of expectations. How can it be cancer, an event so totally unexpected in the life story, a temporal affront so unthinkable it is more shocking than the diagnosis itself? The disruptive force of the event immediately shatters not just day-to-day familiar existence, the "taken-for-grantedness" that is so comforting in everyday life, but also the envisioned future.

In addition, the word "cancer" carries its own story, and hence the ability to shock in its own right. Powerful cultural narratives invoke their power: cancer the dread disease, cancer the killer, cancer the mutilator. Two couples are unable to even say the word to each other. Refusing to name has a primal protective function: if the word isn't spoken, we can protect each other against the encroaching meanings of cancer as destroyer and killer.

Three spouses feel the shock of the diagnosis in terms of an actual physical assault on the body, thus embodying the blow. Brad is "bowled over"; Ned feels like he has received "a blow to the chest"; Rob feels like he's been "hit in the stomach". If I absorb the body blow, will my wife feel less pain? Cultural narratives set about reframing the shock into recognizable meaning: if fighting cancer is a "war", then isn't cancer the enemy and my wife's body the battlefield?

Disorientation/Confusion/Uncertainty

The shock of the diagnosis tears apart the familiar marital narratives. Disorientation, confusion, and uncertainty set in. The comfort of an ordered life is lost. Thoughts immediately go

to the marriage itself: what will happen, what will this mean, how will my partner handle this, will he stay, will she still love me? Uncertainty is registered even as the doctor speaks in words of certainty. Disorientation is reflected off the cold, white walls of the clinic.

The narratives fill with words and actions of confusion and disruption. What lies ahead is a "big mystery" (Brad). The world "turns upside down" (Ellen). The diagnosis "freaked me out" (Gerry). Normal activities can't prevent feeling "out of sorts, disconnected" (Ned and Terri). There is a "constant pressure" (Rob). It feels like "going crazy" (Susan). Brad, Ellen, Gerri, and Rob turn to alcohol, food, and/or drugs to cope. Anger erupts between Gerry and Linda and simmers between Rob and Susan. Individual trauma is interwoven with marital trauma.

The couples struggle with the diagnosis and proposed treatment. Why is the treatment protocol so cut and dried? Why aren't more treatment options presented? Why are we in and out of the office without having had the chance to tell our story to the doctor? Questions about involvement and responsibility present themselves: Why am I accepting this without question? Why is my spouse doing the same? What is my spouse's responsibility in this? Why isn't my spouse out there doing research that could save my life? Guilt, blame, hurt, and disappointment become part of the narrative. A complex chain of meanings arises from a brief initial contact with the foreign meaning system of the clinic.

Something is up with friends. Couples with cancer and friends without cancer are now different from each other. Why isn't this like any other illness? Why should we have to negotiate a way to fit the cancer into our friendships? Distance from friends is mirrored by distance between spouses. Roles change, identities shift.

The realness of everyday routine becomes an anchor. Brad continues with his daily chores; Ned and Terri continue to have an active sex life; Linda tries to maintain order in the household; Rob increases his workload.

Disturbing dreams and images intrude. Cancer has Brad "by the throat". He is "in the dark", it is "sink or swim". Ellen "is in the middle of this quiet". Terri stands in a hot shower but is

"ice cold" and "frozen". She is on a beach playing with broken glass. Gerry is wearing a red coat. Susan has a green blob inside her body. She is paralyzed. She is bleeding profusely.

Embodied confusion abounds. Where is the cancer exactly? What will happen to this familiar body? Why is there cancer when the body looks normal? How can there be cancer in this young and healthy body? What does a changed body mean for the relationship?

Invasion/Intrusion/Presence of Other

As the cancer invades the spouse's body, it also invades the lived world of the couple. Brad and Ellen fight a menacing creature capable of destroying their marriage; Ned and Terri confront an enemy invading their territory. Bodies with cancer become alien bodies, as the presence of other separates the person from the body.

In the threatened territory of Brad and Ellen and Ned and Terri, an alliance is formed to defend and fight and a stance adopted that is proactive and collaborative. Metaphors are of subdual through combined strength and will.

Gerry and Linda and Rob and Susan do not join forces. The invasion is met singlehandedly.

Isolation/Separation/Separateness

From the moment of diagnosis, isolation, separation, and separateness are part of the shared cancer experience. Life together becomes separated between "before cancer" and "after cancer". The course of the marriage is sharply separated into the marriage of the past and the marriage of the present. The marriage is suddenly located within a different reality. Partners, friends, and relatives act differently. The body changes. Daily routines are different. Support from spouse, family, friends, and pets does not assuage a profound sense of uniqueness and solitariness. No one understands.

The marriage is still new, so the demarcation into past and present married lives is especially painful. There has not been time to establish or enjoy the marriage of the past, and now it has been

taken away forever. Isolation and separateness within the marriage are strange, unfamiliar feelings. The close, romantic togetherness and unbounded future of early married life are suddenly threatened.

Now the spouse with cancer is not just a partner, lover, and friend, but also a cancer patient. It seems like no matter how much love, care, and support the caregiver spouses provide, they cannot penetrate the barrier of "other-ness" that now surrounds the partner with cancer. It seems like no matter how much the spouses with cancer appreciate the support, they do not understand what the caregiver spouse is going through.

Ellen realizes immediately that it is "the end of 'my former life'". She and Brad go through the treatment period "very isolated" from each other. Ellen goes back to work and Brad is completely unaware that she is seriously depressed. Ellen despairs at their attempts to regain their former sexual selves. Brad goes doggedly through his daily routine, trying hard to maintain a sense of order.

Gerry and Linda have completely separate experiences of the cancer. Gerry isolates himself from both Linda and his former life. He puts up a wall between them by acting completely differently from the husband she knows. Gerry and Linda don't communicate and they don't have sex. Gerry tries to put up another wall between him and his boss. He reinforces his isolation by retreating into drugs and lashing out in anger.

Ned and Terri lie in bed, consumed with their own private thoughts. Terri keeps her cancer treatment self private so she can conceal her pain. She goes off by herself without telling Ned. Ned and Terri can't connect with their jobs or their friends.

Rob and Susan have no real contact during the cancer treatment period. Sometimes they do not see each other for days. Susan removes herself from the marital bedroom. Her anger is like a wall between them. They remain alone with their hurt and frustration.

Isolation and separation for these young couples has a particularly painful connotation. If we are apart, is it because we are not going to stay together? Is my spouse going to leave me? How

can somebody love me or desire me or want to be with me if I have cancer? It is this meaning that underlies all of the isolation and separation, that lays bare the inchoate fear of abandonment.

More and more, there is a sense of separateness from friends. It is expected that there will be a certain amount of distance in the face of unfamiliarity and confusion. It is not expected that there will be an apartness, a different stature, a new identity. Other young couples have problems, but they don't have cancer. No one can possibly understand.

The couples look for ways to make sense of their isolation, separation, and separateness. Ellen thinks to herself, Brad can't understand because he's a man: it's not his fault. Linda excuses Gerry's withdrawal: after all, he's just had cancer. Ned lets Terri be the warrior on the solitary quest, even though he wants to be. For Rob and Susan, the solitude in personally productive but compounds their loneliness.

Dissonance/Disruption/Incongruity

The cancer does not "fit". It does not fit now and it does not fit here. It is harsh, disharmonious, discordant. It is strange, weird, ridiculous. Why doesn't the dissonance ebb or recede, like the shock and confusion do?

Three types of dissonance are almost universally registered. First, the experience is cohort-dissonant: it is a totally unexpected event at this particular time in life. The consequential meaning is a profound sense of intersocial disruption that creates a disengagement from the peer group. Second, the diagnosis is lifestyle-dissonant: it is not congruent with the active, health-conscious lives being led. The consequential meaning is a loss of faith in causality and individual control. Third, the diagnosis is genetically dissonant: there is no cancer, or only minor cancer, in the immediate families. The consequential meaning is a sense of unfairness and indiscriminacy.

Domain Two: Marital Cohesion

Collaboration/Reciprocity/Responsibility

True partnership can take years to establish. Young adults are still seeking to understand the nature of marital obligation, duty, responsibility. Marital vows are words, not yet deeds. Marital fealty is an idealized, romantic bond. No decalogue of marital rules governs moral actions. Collaboration is understood in terms of building marital security. Individual narratives remain strong, embracing separate plots of personality development, career opportunity, family obligation, social establishment, and existential positioning.

Cancer changes all that. Couples instinctively realize that this is the big test. The challenge is clear: find a way to make the cancer experience a partnered one even if you are still working out the rules of partnership. Come together and throw everything you've got at the cancer even if you don't know what you have to throw. Construct a mutually authored story even if it wasn't mutually enacted.

Upon diagnosis, flight or detachment from the cancer presents itself as an option, with no thought in that fleeting moment about collaboration or obligation. Brad, Ned, and Terri imagine running away; Gerry actually removes himself in spirit from his regular life. These responses are momentary escapist fantasies, not the end of the story. No one runs away. All of the non-affected spouses accept that it is their role to keep things going and that this will mean extra duties. All of these spouses ascribe meaning to their activities, seeing them as a way to maintain not just normalcy and a quality environment but also connectedness and cooperation.

Each couple struggles through the cancer treatment period. Responsibility and connectedness are not enough in themselves to ensure a mutual construction of meaning. Adjustment and recovery are elusive, mutable concepts. There is a sense that each narrative could "go either way", as Ellen felt throughout the experience.

Three of the narratives are collaborative, reciprocal, and show a shared responsibility of construction. For Brad and Ellen, Gerry and Linda, and Ned and Terri, these are true co-narratives.

The story told has a consensual plot and the authors exhibit mutual emplotment throughout. Minor differences of fact are accepted and incorporated. Major differences of situation and experience are contextualized in a mutually acceptable way. There is a sense that collaboration has been the *sine qua non* of the experience all along.

Brad and Ellen differ about cancer having control over them, but find a way to agree about how they met the power of the cancer with the power of their strength. Ned and Terri disagree about how long their post-treatment malaise lasted and why it happened, but incorporate this as a mutual learning experience rather than an obstacle. Gerry and Linda have completely divergent attitudes toward sickness, but allow themselves be different and still maintain a unity of purpose. Differences are a distinctive, not destructive, part of marital identity. Reciprocity of intent fosters acceptance of disparity. Through a shared recounting, differences are seamlessly incorporated into the marital history.

Full of hostility, disunity, and isolation, Rob and Susan's narrative is a collaboration of sorts, but has no reciprocal understanding. These are two individuals who are co-authoring a story of hurt, disappointment, and loss. Nevertheless, their story arises out of shared experiences and represents a mutually constructed marital history.

Responsibility is the fulcrum of these cancer experiences. Cancer first presents these couples with a choice: to confront the fact that the experience might shake the marriage to its foundations, or to ignore it. These couples face this responsibility head on, immediately accepting that the experience is going to affect their marriage. Every spouse becomes part of the task of resolving this issue, and accepts responsibility for doing so. And from that point on, each spouse takes personal responsibility for getting their spouse, themselves, and the marriage through the cancer experience as best they can.

Devotion/Loyalty/Constancy

There is an eloquent omission in these narratives: love. It is rarely mentioned, and yet

unmistakably present. Most importantly, it is present not in spoken words or romantic gestures but as a steadfast devotion, a deep loyalty, and an unwavering constancy.

Hope/Optimism/Positivity

Hopefulness and optimism illuminate all of the narratives. Hope is a complex, highly subjective entity, taking on many meanings in the cancer experience. Hope is a signifier of health, and those who are optimistic are healthier. Hope is a representation of positive thinking and can effect disease outcomes. Hope is a shield against negativity. Hope is a shared understanding of the world. Hopefulness belies hopelessness.

In these shared cancer narratives, hope does not have to be explicitly spoken or described. Hope does not have to have a particular object or outcome as the goal. There is an indistinct, generalized sort of hope, more reactive in stance but proactive in terms of intended employment. Hope is not "I hope I don't have to lose my breast" or "I hope I can find a miracle cure". Hope is more a dynamic life force, a glass half full, a sightline that contains a fully realizable marital future.

Hope is also a focus, a gathering of intentions. Hope preserves the cherished goal of restoration. Ellen and Brad hope that honesty will survive anguish, that Ellen will bring life back to normal when she returns to work, that chemistry and passion will endure. Gerry and Linda hope that withdrawal does not mean defeat, that words spoken in anger can be forgiven, that an emotional meltdown will not lead to a marital breakdown. Ned and Terri hope that they can protect each other from pain, that they will be able to handle sexual differences, that they can return to their former marital life and just pick up where they left off. Rob and Susan hope that they can find understanding for their individual limitations, that they can face their deep feelings of hurt, that they can repair the damage to their marriage and realize possibilities still unspoken.

Hope and fear are formidable opponents in cancer stories. It might also be said that without fear and distress, there would be no need for hope. In these cancer narratives, distress, and therefore fear, gets its acknowledgement but at the same time does not threaten hope. Ellen is angry

and frustrated most of the time with Brad, but hopes he will continue to provide solace with his presence. Gerry is devastated by having to reveal his secret, but hopes Linda will somehow understand. Terri is sad about the loss of her body as she knew it, but hopes it hasn't changed her sexual relationship with Ned. Susan cannot look at a child without feeling pain, but hopes that someday she will be able to think about adoption. And so hope and distress coexist without compromising the sacrosanct place that hope occupies in each narrative.

Connectedness/Compassion/Empathy

Family connectedness is a leitmotiv in these stories. All of the couples speak often and lovingly about how supportive their families are. There is a deep connectedness that finds expression in steadfast, day-to-day support, but has a more important meaning. This is a kind of "independent dependence", a connection to parents and siblings that allows the marriages to maintain autonomy in the face of needing help.

As the treatment protocol is accepted, the spouses with cancer are obliged to give up their regular schedule of activities to focus on treatment and recovery. The caregiver spouses take on the burden of managing practical domestic matters, providing emotional support, and living with a person who is ill. In this way, Brad and Ned stay intimately connected and involved. Linda searches for a way to restore connectedness. Rob shoulders more responsibilities, hoping it might give him a chance to stay connected and to show connectedness.

Moments of compassion and empathy between spouses touch the heart and show an even deeper level of connection. Brad tries to put himself in Ellen's shoes, tries to imagine what it would be like to have a body part cut off, tries to understand what she's going through. Ellen is tormented by her isolation and feels Brad can't possibly understand, but in the midst of her turmoil wonders how her husband is coping. Some time later, she starts her "real" recovery by thinking about what Brad went through. Linda hears something in Gerry's voice that breaks her heart. She tries to understand his fear of cancer. Ned thinks about Terri having to endure treatment and tears come to

his eyes. Terri tries to spare Ned from having to see her pain. The gentle presence of pets provides unconditional caring. Compassion and empathy allow a true sharing of the pain of the experience.

Humour/Playfulness/Fun

Black humour, gentle teasing, silliness, whimsicality, irony, Superman analogies, Monty Python, champagne in bed, comical-looking pets...all represent humour and frolic as a way to cope, but more importantly are a link between pre-cancer identities and new lives. Humour proves that the relationship has survived and has remained more or less intact and familiar.

Three of the couples were bonded through laughter from the start of their relationships. Brad can always make Ellen laugh; Ned tries to break Terri up even as they cry together about the diagnosis; Gerry and Linda find their way back to each other and soon are sharing jokes. Humour is instrumental in Gerry's self-discovery: he pokes fun at himself, he recognizes the humorous side of his phobia, and he points ruefully to the irony of fate. There is a sense that humour is in itself a powerful means of communication, allowing painful feelings and thoughts to be expressed in a way that is both comforting and comfortable. It is a telling indication of the pain reflected in Rob and Susan's narrative that it is so starkly devoid of humour.

Domain Three: Resolution and Gain

Acceptance/Accommodation/Grace

Cancer is uncommonly difficult to accept. Denial offers protection against pain. Facts and realities retreat against the power of emotions and images.

Denial of cancer has no place in these cancer stories. There is an uncommonly strong strand of acceptance running through the narratives. These are strong, intelligent, accomplished, assertive individuals: passivity is not behind this acceptance. The diagnosis is accepted for what it is, without any of the "it must be a mistake" or "I want a second opinion" sentiments often expressed. No attempts are made to find a miracle cure. No one goes into denial about the existence of cancer. No one bargains with God. Shocking though the diagnosis is, it is accepted.

Little effort is expended on developing an a priori cause for the cancer, usually one of the first steps in restoring coherence to a world turned upside down. Cancer makes an enormous impact on these couples' lives, but they do not put their psychological energy into answering the question "Why did this happen to me?" or "Why did this happen to us?". Rob makes a sarcastic reference to Susan's cancer being connected to riding horses, but Susan does not take up this etiological challenge. The couples accept that cancer has happened, that it has happened to them, and that they have to move on to dealing with it as best they can. The meanings that the cancer subsequently takes on, therefore, cluster around the effect of the disease rather than the cause.

Changes in physical bodies and the resultant effects on perceptions of gender and sexuality are struggled with but accepted. In three of the narratives, the cancer treatment results in profound physical changes for the affected spouses. Ellen and Terri retain a sense of wholeness despite losing a part of themselves; their husbands perceive mainly a cosmetic difference. Rob and Susan have not yet completely absorbed the consequences of their loss, but have accepted the reality of what happened.

Acceptance depends on interpretation of the event. The meanings that Ellen, Terri, and Susan ascribe to their loss is deeply connected to their spouse's attitudes. Brad and Ned do not expect that any essential change will happen, whereas Rob is fearful from the beginning about what changes might take place; Brad and Ned help their wives confront the reality of their changed bodies, whereas Rob keeps his distance; Brad and Ned continue to see their wives as sexually desirable, whereas Rob does not know how to deal with the changes in Susan's sexual identity. Rob's stance toward accepting illness into his life, as determined by prior experience with his mother's heart disease, causes discomfort, even squeamishness, with Susan's illness, especially the embodied part of it. Meanings learned in the family context cause severe disruption in the marital context. For Linda and Gerry, the physical changes are minimal; Linda, however, accepts the cancer readily and in fact is the only spouse not surprised by the diagnosis.

The above constructions of meaning are inextricably connected to each individual's

perception of embodiment and the acceptance of disease as a bodily reality. There is a sense in three of the narratives (Brad and Ellen, Ned and Terri, and Rob and Susan) that the cancer is not just unexpected, but an occurrence of body failure in bodies that should not have failed. This is the one area in which acceptance has not occurred, but for which accommodation has been made. There may be a feeling of shaken faith, because healthy lifestyles and good genes have failed to protect these bodies from cancer, but there is also a willingness to relinquish past conceptions of embodied self and accept new ones.

Accepting cancer is often an existential exercise. Each person finds unique questions to ask, contemplates different aspects of life. Brad, with a lot of solitary time to think while doing chores, thinks about how many people and animals depend on his presence in the world. Ellen goes on a retreat, sees her situation in a new light, and discovers the spiritual value of gratitude. Gerry goes through an agonizing, isolated period in which he questions his whole life, including his marriage and his job. Linda is shaken by Gerry's behaviour and questions the reality of her marriage. Ned and Terri experience a spiritual dimension in sex. Rob asks himself "What's the point?" in regards to all his hard work. Susan finds comfort in meditation and wonders whether her life is going in the right direction.

Acceptance and accommodation imply a forgiveness of the imperfection of self and other. This state of grace arises out of each spouse's struggle to keep from turning the inevitable pain and resentment of the cancer experience into condemnation and enmity. Accommodation of exterior change both arises from and contributes to an interior accommodation of new feelings, beliefs, and values, a cyclical process that is ongoing.

Creativity/Flexibility/Adaptability

It is a truism that cancer necessitates individual and interpersonal role shifts that challenge the very core of the self. When enumerated, however, the arduousness and profusion of the role adjustments for these spouses are striking:

- Brad does not understand the importance that Ellen places on her role in the workplace
- Ellen dreads taking on the role of dependent sick person in her family
- Brad realized how many people and animals depend on his role as the "Rock of Gibraltar"
- Ellen has to redefine her role as a strong, independent woman
- Brad is confused about his role as sexual partner
- Ellen mourns the loss of her role as an assertive sexual partner
- Brad feels like he is the villain when he is trying his best to be heroic
- Ellen feels pressured to take on the role of cancer survivor when she isn't ready to
- Brad tries to be Ellen's protector but knows she is uncomfortable with that role
- Ellen is able to step back into her role as wife when she realizes what Brad's role has entailed
- Gerry abdicates his role as active marital partner
- Linda takes on the additional role of marital caretaker
- Gerry reverts back to his high school self as a protective, safe role
- Linda wonders if Gerry's previous role was a sham
- Gerry doesn't want the role of coward
- Linda is placed in an uncomfortable new role with friends
- Gerry is able to accept a new role as "cancerphobia poster child"
- Linda realizes that she brings her manager's role home from work
- Gerry is forced to acknowledge his role as someone with cancer who may have a recurrence
- Linda takes on the role of health watchdog
- Ned steps immediately into the role of Terri's protector
- Terri has to give up her role of potential mother
- Ned maintains his role as jokester in the face of trauma
- Terri approaches her cancer in the comfortable role of project manager
- Ned takes on new roles around the house
- Terri puts on a brave face, playing a role she thinks is expected of her

- Ned worries that his breadwinner role is diminishing
- Terri experiences a dramatic role change at work
- Ned's role with his male friends changes
- Terri's friends continue to place her in the sick person role
- Rob cannot fulfill the caregiver role Susan expects of him
- Susan agonizes over not taking on a more proactive role after her diagnosis
- Rob thinks he has to take on the role of financial steward
- Susan will never take on the role of pregnant woman
- Rob thinks he might never play the role of father
- Susan's role as her family's top athlete is in doubt
- Rob leaves his social roles behind
- Susan is intrigued that she still sees herself in the role of attractive woman
- Rob doesn't accept his role as unfaithful husband
- Susan is a prisoner in a sanctuary of her own making

As the spouses try to adjust to these role changes, the marriage itself goes through role and identity changes, putting additional pressure on each spouse's sense of self. Some of these changes take place within the family context, such as Ned and Terri taking on less responsibility. The most important role changes, however, take place within the peer group context:

- Brad and Ellen feel that the cancer experience has set them apart from their circle of friends
- Gerry and Linda feel awkward around their friends
- Ned and Terri feel a sense of distance from their friends
- Rob and Susan feel they don't fit in with some or all of their friends.

The experience of cancer also has a powerful identifying effect on the couples that is embedded in the affected spouse's identity as a cancer patient and survivor. The couples now (and possibly forever) live within their identity as a cancer-affected couple, even though they are well past the treatment period. Various forces combine to entrench this. Remembered experience is

powerful and indelible. The possibility of metastasis and recurrence is a constant reality. The iterative process of medical follow-up is unavoidable and establishes a continuing identification with cancer patientness.

For these young couples, however, identification with cancer is mostly about social positioning. These couples face the unexpected, irreversible reality of feeling set apart from others in their immediate peer group by virtue of being "the couple who had cancer". In the social narratives of friendship, these couples are now "the friends who had cancer". Old people have friends who have cancer, not young people. Being young is about having fun, travelling, parties, sports; it is not about hospitals and medicine.

The couples are tired of all the role shifts demanded of them and want to return to their familiar social enclave. It isn't possible, and they must make yet another role adjustment, to adjust to a new, unchosen, unwanted marital identity within a peer group in which identity is all-important. The challenge to find creative ways to adjust, to remain flexible and adaptable, continues.

Pride/Respect/Heroic Stature

For Brad and Ellen, Gerry and Linda, and Ned and Terri, telling the cancer story is an opportunity to express pride about their marriage. Brad and Ellen are proud that they went through the cancer experience and "did OK with it, learned from it", that they "passed the test", that now they are "Super Couple". Gerry and Linda are proud that they faced their issues with honesty, that they have such a high level of trust, that they are "getting there" in building the perfect marriage. Ned and Terri are proud that they faced the cancer with courage, that they survived the "long trek", that they have the most secure marriage that they know of. For Rob and Susan, they cannot feel pride in a marriage that both are so unsure of: Rob is not sure if the marriage is "just normal, or wacko"; Susan continues to compare her marriage to her parents'.

Most stories have a heroic element, and that is especially true of these stories. All four of the non-affected spouses express admiration and respect for their spouse's courage and strength in

the face of the cancer. Ellen, Gerry, Terri, and Susan are heroes to their spouses. This is earned heroism, not romantic heroism. Brad, Linda, Ned, and Rob were there through the whole experience; they know, or can imagine, what it took. Their spouses are much more than just survivors.

Maturity/Growth/Readiness

Marriages cannot survive the kind of emotional turmoil, isolation, disruption, and role and identity changes associated with cancer if husbands and wives do not have the necessary individual resources. The overwhelming number of adjustments and changes these couples went through could not have happened if each individual spouse had not had a strong sense of self-identity, a solid foundation of self-esteem, and a healthy amount of self-confidence. These qualities gave each husband and wife a level of maturity that allowed them to think and act intelligently and expediently in both their own best interests and those of the marriage.

Maturity is evident in these narratives in many manifestations. The couples accept the truth of the diagnosis. They are active, not passive, in relation to the cancer. They accept dependency and yet maintain independence. They put aside their own needs to help others. They extend their range of behaviours and skills. They attend to the demands of the present without forgetting the past or neglecting the future. They show equality. They strive for harmony. They cherish unity.

Cancer tests maturity, but it also bolsters it. These couples feel different from their friends because they ARE different: they are more mature. They have been through an enterprise of great significance and have endured. They have taken on roles for which they had no models. They have behaved honourably and nobly in the face of fear. They have given new meaning to love and commitment.

Out of such newfound maturity and growth comes a sense of readiness. Brad and Ellen, Gerry and Linda, and Ned and Terri all make this point explicitly: they have survived cancer, they can face anything now. Although Rob and Susan do not yet feel a mutual readiness, they are

situated within individual maturity and readiness states that may well provide the nucleus for cooperative growth.

Control/Empowerment/Mastery

The cancer experience is full of contradictions. The patient feels totally out of control, at the mercy of the disease and under the authority of medical personnel, and at the same time feels in control of the outcome. The patient feels at the mercy of some unseen, multiplying bunch of cells, and yet is still physically in control. The patient can give up control, take control, or find a workable compromise.

These couples find the compromise. They allow themselves to feel helpless and confused but centre themselves more within a sense of personal control than within a sense of powerlessness. They invest in a positive outcome for the illness experience itself and for how that experience will impact their relationship. Even Rob and Susan, so estranged through the cancer period, remained in control of their individual processes and emerged convinced of their love for each other and their future together.

Keeping the locus of control firmly within the marriage is a priority for all the couples. Brad and Ellen firmly resist Ellen's mother's doom-saying; Gerry and Linda seize the opportunity to open up as a couple to a friend; Ned and Terri plan a very personal celebration of the end of treatment; and Rob and Susan remain together under one roof despite severe tension and hostility. Although the presence and influence of outsiders is a constant factor, coping and adjustment remain a marital responsibility.

Maintaining control while accepting that certain things are beyond control makes empowerment and mastery possible. The individual spouse becomes subsumed in the cancer experience as a cause or idea that is greater than the self. The narrative that emerges from such a shared optimal experience becomes suffused with the meaning of a greater goal.

Chapter IX

DISCUSSION

As a qualitative inquiry into the meaning of cancer, this study joins a growing body of research which declines to accept the biomedical assumption that illness represents pathology. For decades biopsychosocial researchers, wielding diagnostic measures such as the DSM IV and other assessment tests, have continued to orient themselves as observers of morbidity. In 2000, for example, Baider & Kaplan De-Nour, perhaps the preeminent researchers on the impact of cancer on spouses, called for additional research on such topics as "contagious effect of psychological distress", "dysfunctional coping", "gender differentiation", and "victimized populations" (Baider & Kaplan De-Nour, 2000, p. 49).

The "distress model" philosophy described above is deeply entrenched in the literature of psychooncology and psychotherapy. As Mathieson & Stam (1991) have observed, psychosocial oncology would be better served by putting less emphasis on diagnosis and classification of psychological disturbance and greater emphasis on understanding the lived experience of cancer patients. Every counsellor must, of course, be vigilant in assessing depressive symptomatology, as it is well known that depression and anxiety are common psychological reactions to cancer (Massie & Holland, 1989). Clearly, however, a pathologizing approach would have failed to capture the actual preoccupations of the participants in this study, for whom distress was only one in a complex web of interwoven meanings.

Notwithstanding the above, this study confirms, in whole or in part, many of the research findings reported in the biopsychosocial literature, including 1) that spousal distress has a reciprocal effect; 2) that interpersonal variables in marital relationships are equally as important as individual variables in coping with cancer; 3) that spousal support is a significant factor in adjusting to cancer; and 4) that marital quality and satisfaction can effect psychological adjustment to cancer. Other findings in the study differ from those in many biopsychosocial studies. One example is the

observation that, at least for this sample of young couples, family members were equally as important as spouses in terms of practical support; this and other differences may be anchored in age-related variables that have not been previously considered.

In considering the impact of cancer on the young adult age group, this study is squarely in agreement with those studies that show that age can be a significant factor in the cancer experience. Most previous studies, however, have not reported the high levels of concern and distress about changed social relationships and cohort dissonance as was found in this study. Other major stressors associated with age group that have not been noted in previous research but which emerged clearly in this study were confusion about the importance and/or direction of career, loss of the perception of unlimited marital possibility, and dissonance regarding the appearance of cancer at an unexpected time and within a health-conscious context.

Although the research in this study is organized around a narrative approach, it indirectly confirms many observations found in the adult development literature. In particular, it supports the view that cancer has a tremendous impact on the developmental tasks of the young adult population, especially career and economic independence, emotional growth, capacity for intimacy, and formulation of identity. It confirms those developmental writers who note that delimiting of future horizons and peer group isolation are a particular threat to young adults with cancer. And it supports those developmental theorists who stress the importance of family attitudes, beliefs, and coping styles in the cancer experience outcome.

This study does not support those theorists and studies that have conceptualized the cancer experience as a stage-based, linear process. In particular, recovery in this study is identified not as a neatly defined phase but rather as an ephemeral, ongoing process dependent on the meanings given to the various manifestations of the illness. Since these meanings can change over time, so too can the orientation of the individual towards his/her perception of recovery.

It is with the existential-phenomenological and narrative literature on the experience of cancer that this study is most in agreement. Even a superficial reading of the narratives shows a

striving to find meaning in the cancer experience and an impulse to frame that experience within story form. What is unique about the findings in this study, however, is the nature of the meaning-making process for the young married participants, a process that had less to do with questions of mortality, spirituality, and ultimate purpose in life than with questions about the impact of cancer on unrealized marriages, careers, social relationships, and future plans. Thus, while these stories confirm the power of narrative as a way to elicit universal themes of meaning, they also reflect a very different group of meanings than many other narratives of cancer.

Implications for Theory and Practice

Among approaches to clinical reasoning, the distress model so often encountered in the literature represents a well-established example of diagnostic reasoning, in which deficits are identified and hypotheses presented about their cause and nature. The types of interwoven meanings revealed in this study, on the other hand, were obtained through interactive reasoning, which, when transferred to the therapeutic setting, would provide an understanding of the clients' experience of illness, how that experience is affecting their lives, and how the interaction between therapist and client might effect outcomes (Mostert et al, 1996). This approach might be especially effective with young adults, for whom social interaction is a major life course preoccupation.

The existential and phenomenological concerns of people who are experiencing or have recovered from cancer is not a well-developed topic in the psychooncology field. Because caregivers and professionals alike understandably prefer to encourage hope, optimism, and a positive outlook, they are often reluctant to discuss serious questions of meaning. This may be even more pronounced when dealing with younger adults, with the result that "young cancer patients who have little experience with poor health and are confronted with mortality may not receive the help they need from medical or psychosocial oncologists to verbalize and work through their fears" (Roberts et al, 1997).

The findings presented in this study corroborate that younger adults go through existential

questioning when faced with a cancer diagnosis, even if that diagnosis does not indicate mortality. A more significant finding, however, is that this existential exploration is profoundly influenced by the particular marriage context in which it occurs. Thus the cancer-affected spouse, while dealing with other marital strains that may arise, is also having to contend with mortality issues that he/she feels are inappropriate in the young adult, newlywed context. Certainly more research needs to be done to determine the special form these mortality issues may take in young adults and to explore the effects of this contextual dissonance on marital adjustment. In addition, therapists working with young couples need guidance in how to encourage discussion of this neglected issue in order to normalize and legitimize concerns which are too often dismissed.

Moreover, it appears from the data in this study that young married adults go through a unique process of grieving when confronted with cancer. Although for older people this might have more to do with the threat of impending death, for young couples it involves the threatened loss of cherished dreams, goals, beliefs, and ambitions. With this loss comes a concurrent loss of a particularly valued part of the shared newly-married consciousness, namely the romantic ideal of endless marital possibility. Counsellors working with this difficult issue are essentially doing grief work, and must understand the unusual permutations of this type of socially embedded loss.

It is important to note that such concerns as described above do not take the usual form of existential inquiry. Older individuals with cancer often look back on their lives, searching for answers about causality or seeking purpose in their existence in order to establish a sense of control. For the young adults in this study, questions of causality were largely immaterial, and did not serve as the main precipitant for self-exploration. Although Wallston et al (1987) have said that causal attribution is a major theoretical basis in the concept of perceived control, this may not be applicable to all populations.

Although this study comprised only four case studies, it clearly was able to produce a significant number of themes that illustrate the many complex meanings given to the cancer experience by young married couples. As McGrath (1988) has pointed out, it is important for

clinicians to assess illness as potentially "a problem of meaning". The schedule of inquiry used in this study can contribute to the small body of clinical literature that offers guidance in eliciting rich interview data on the meanings of cancer, such as Houldin's (2000) meaning-centred questions, as well as provide additional thematic material for more structured assessments of meaning such as Fife's (1995) Constructed Meaning Scale.

When the personal meanings of the illness experience are known to the counsellor, it is possible to better understand the cancer-affected person's responses to the illness (McGrath, 1988), the effect of the newly-constructed meanings on the previous meanings or life themes that were of central importance in the person's life (Fife, 1994), and how the new meanings might affect the process of adaptation (Moss-Morris & Petrie, 1994). Thus, the counsellor's understanding of the pre- and post-cancer meanings can serve as the foundation for therapeutic intervention, with the counsellor tailoring the assistance given to the expressed and dormant meanings revealed in the counselling dialogue. The counsellor working with young married adults must be especially careful to attend to positive meanings that are capable of restoring and buttressing both intrapersonal and interpersonal well-being.

The above issue is especially relevant with regard to negative meanings, which the counsellor should monitor through ongoing assessment, identification of harmful coping mechanisms, support in the reframing of meaning, and appropriate referrals (Germino et al, 1995; Houldin, 2000). Considering the relative vulnerability and immaturity of a new marriage, the types of shock, anger, and loss experienced by the participants in this study, and the potential for long-term damage to the marriage bond, counsellors should be particularly alert for negative meaning construction and associated harmful adaptation. Some of the themes revealed in this study, such as disorientation, isolation, and dissonance, point to schemas that in certain couples could obstruct adaptation.

In his theory of logotherapy, Frankl (1984) identified work, love, and self-growth as the three major sources of meaning in people's lives. It is revealed in this study that Frankl's view is a

particularly apt theorization on which to base any phenomenological study of young married adults, for whom all three concepts have a central, heightened meaning and for whom all three are inextricably connected. It is essential that counsellors working with young married adults understand how deeply the cancer experience can affect these three central sources of life meaning, perhaps more deeply than for any other age group.

It is also surmised that the research in this study could provide suggestions to oncology counsellors for therapeutic intervention topics. One example from the research might be the revelation that some of the cancer-affected participants resented the expectation from their spouse that they should at some normative point be in "recovery", since for them the meaning of recovery represented not the end of treatment and the absence of symptoms but rather a release from the near-constant, intrusive thoughts of the illness experience. Another example is the feeling on one participant's part that her anger was a beneficial part of her cancer experience and indeed was the most meaningful source of her strength, while her partner reacted to her anger with distancing and aversion. Armed with such knowledge of the private, unexpressed meanings given to concepts such as recovery and anger, counsellors would be better able to plan interventions that attend to the deeper level of the cancer-affected spouse's interpretive processes and at the same time facilitate communication with the non-affected spouse.

From the above we can see that personal meanings, although they may be a valuable part of the individual spouse's experience of cancer, can also be a divisive influence if misunderstood or withheld. These differences in understanding, at a time when most couples are still establishing effective communication, can, like the cancer itself, change a previously healthy entity into a seriously compromised one. Alienation and misunderstanding between newly married couples may be particularly corrosive, as the relationship has not yet had time to cement the marital bond. As Fife (1994) notes, every family member must face the changed meanings, both individual and shared, that are the result of the illness. A counsellor working with young married couples, therefore, can provide invaluable assistance in opening a dialogue about these changed meanings

and helping negotiate their acceptance both within the marital dyad and within the family network.

In most cases, young married adults still have an intact family constellation which may be involved in varying degrees of proximity with the cancer experience. Even without this proximity, generational patterns of dealing with illness could have more of a hold on young spouses than on older ones. This study has shown how parents and siblings can be a major source of support but can also cause problems, both between spouse and family and between the spouses themselves. Counsellors will need to address the complicated issues of independence and role identity, as they arise within the matrix of family illness narratives, so as to ensure that the young married couple is able to continue their pursuit of separate goals and identities.

Cancer has become socially constructed around such values as coping, hope, and recovery, and people with cancer are expected to adopt this ideology (Gregory & Russell, 1999). The findings from this study suggest that this may be especially problematic for young married adults, for whom the disparity between their own suffering and the social pressures to be positive and optimistic may be greater than for other social groups. Counsellors must retain an awareness that, regardless of outcome, younger cancer patients may suffer as much or more as other patients, and that a major consequence of suffering may be the erosion of communication and a concurrent distancing of affections.

The issue of suffering is worth discussing, if only because it is so often avoided or spoken of in the guise of "distress", "adjustment difficulties", "pain management", or "psychosocial concerns". It is also an area that was not considered at the outset by the researcher. The concept of suffering is an elusive one; Geertz (1966) suggested that it occurs when a meaningful life pattern threatens to dissolve into chaos. Several observers of illness (Amato, 1990; Cassell, 1982; Gregory & Russell, 1999; Kleinman, 1988) have drawn our attention to suffering, showing how religion and medicine have appropriated the concept as a problem to be treated with doctrinal explanations or palliative medications. Modern professional caregivers, seduced by the nil desperandum ethos of medicine, have been trained to treat each locus of suffering separately, which minimizes and

sanitizes the suffering and allows the caregiver to maintain a safe distance from the human anguish that suffering represents.

Although suffering was not originally a research consideration and did not present itself as a *prima facie* narrative theme, it is clearly a topic which should be considered. Running throughout the narratives in this study, the theme of suffering interlaces the physical, emotional, and psychic pain of the cancer experience into a single strand of meaning. Never directly addressed, this type of overarching meaning gives cohesion to many disparate themes. Counsellors working with the young adult population could expect that, as in this study, suffering will be expressed only in oblique and metaphorical ways, testament to sociocultural meanings that stigmatize cancer and suffering in young, otherwise healthy adults with an excellent prognosis. Working with young couples, therefore, might entail creating an environment in which suffering can be overtly voiced. And it must be remembered that, although many disease-free years of life may follow a young adult's cancer experience, the cure of disease does not always eliminate suffering (Cassell, 1982).

One particularly salient research observation that arose in this study was the degree of isolation and separation experienced by the couples. Kleinman (1988) has shown that the act of labeling someone as a cancer patient is sufficient to "encase the patient in a visible exoskeleton of powerfully peculiar meanings" (p. 22). Other theorists, following Van Gennep's (1960) concept of the liminaire stage in social anthropology, have used the term liminality to describe the state of alienation and disruption that results when an unwilling, unprepared individual is suddenly required to make sense of an illness, come to terms with mortality, and confront the entropy of the future (Frankenburg, 1986; Little et al, 1998; Murphy et al, 1988).

Based on the findings in this study, it is postulated that this theory has special aptness for young married adults. The sense of alienation, disruption, apartness, and existential turmoil experienced by this type of individual has special power within the contexts of a vibrant romantic partnership, a thriving social network, and a life untouched by intimations of mortality. For this group the experience of liminality can be expected to be more unsettling, with the danger that a

failure to adequately process its meanings will lead to a phase of sustained liminality. For counsellors, liminality provides a category of understanding which captures the "big picture" of the young cancer patient's worldview.

If illness is viewed as a "state of disharmony...which incorporates a loss of the familiar world" (Toombs, 1992, p. 96), then it can be said to cause a sense of spatial and temporal disruption. While spatial disruption was evident in this study, it seems that young married adults are more affected by temporal disruption, that state of being that results from an unexpected shift in the life course. Couples may find themselves so caught up in the demands of the here-and-now that they cannot move freely between the actual order and the possible order in order to project themselves into the future moment to "possibilize" (Zaner, 1981). As Cassell (1982) notes, the meaning of the illness time scale is subjective and varies with every patient. Counsellors, therefore, in aiming to restore the identity of the young adult marriage as a temporally lived entity, must be particularly attentive to determining how cancer has impacted the couples' sense of future possibilities.

The findings from this research study may also contribute to disciplines such as health psychology and medical sociology. By helping to illuminate individual and spousal conditions and issues and the constructs and meanings underlying them, this research can add to the data set of case studies on the restoration of psychological health and the social construction of illness dialogues.

These narrative case studies could also be used to guide practice in the oncology setting. Many of the participants in this study expressed considerable dissatisfaction with their treatment by representatives of the medical profession. It is hoped that even such a small number of subject cases as these might serve to alert oncology professionals to possible shortcomings in their treatment protocols. As Kleinman (1988) states, clinicians need to be able to hear the "complex inner language of hurt, desperation, and the moral pain (and also triumph) of living an illness" (pp. 28-29).

It must be noted that the above discussion of implications for theory and practice addresses only those issues pertinent to the relevant therapeutic population, namely young married adults. As was evident in the narrative analysis, many of the issues that arose in the interviews had a broader application, indicating that the narrative themes revealed here may be highly relevant to other populations.

In conclusion, this study makes a contribution, no matter how small, to the growing belief in the oncology field that clinical practitioners can provide an authentic presence by being an empathic listener to cancer stories. Getting to know cancer involves hearing both the suffering and the life affirmation and listening to the meanings inherent in each. In essence, cancer challenges us to understand the human condition as it is found simultaneously in vulnerable, diseased bodies and invulnerable, resilient spirits.

Limitations of the Study

In any discussion of the limitations of empirical inquiry, it must first be recognized that the endeavour is inevitably subject to the researcher's own limitations. Although I have attempted to minimize this through participant validation and external review, it is always true that as researchers we interpret participant data through our own personal, cultural, and social filters. In addition, the researcher's interview presence, choice of questions, and analysis of selected narrative themes help to create what Kleinman (1986) calls the "clinical reality" of interpretation.

Any methodological standpoint is, by definition, "partial, incomplete, and historically contingent" (Riessman, 1993, p. 70). Like every method, the narrative model is subject to limitations which, while they do not detract from the valuable information produced in story form, can affect the strength and comparability of the research findings. As narrative researchers we can never escape from representation or from reduction, and every method exacts some price in the form of truth no matter how meticulous the researcher's process. As Mitchell (1990) has said, there is an inevitable gap between intention and realization, between original and copy.

It has been observed that "secrets inhabit narrative as a matter of course" (Charon, 1993). Through the act of interpretation, the researcher tries to divine the secrets of the narrative text, but in the end this must inevitably be an exercise not of truth but of conjecture; in Lacan's words, "truth always manifests itself in a structure of fiction" (in Davis, 1983). Thus the narratives produced in this study are merely a textual approximation of a transient reality and not, as some narrative analysts make the mistake of assuming, "untrammelled access to a realm of hyperauthenticity" (Atkinson, 1997, p. 10). As Kermode says, "We glimpse the secrecy through the meshes of a text; this is divination, but what is divined is what is visible from our angle. It is a momentary radiance" (Kermode, 1979, p. 144).

Although the temporal and contextual ordering given to a narrative by its creator is in itself a significant way of conferring meaning (Ricoeur, 1981), the researcher, constrained as he/she is by the imperatives of the text, cannot hope to capture the intrinsically ephemeral nature of storytelling. Because the semi-structured interview embraces such a high degree of participant freedom and creativity, the story as told is very much located in the moment, with an infinite variety of temporal shifts, somatic adjustments, ambiguities, contradictions, forgetfulnesses, attitudes, tones, gestures, and so on that are encapsulations of meaning in their own right. And because illnesses like cancer can provoke such a wide range of responses, cancer stories are replete with multiple contradictory voices. Derrida has said that our task as analysts is to deconstruct such oppositions in order to "recapture the unity of gesture and speech, of body and language, of tool and thought" (Derrida, 1974, p. 85). Although the narrative method may be one of the most effective in achieving such deconstruction, it is nevertheless limited in its ability to capture the multifacetedness of the storytelling experience.

As we have seen, the four narrative accounts produced by this study have revealed many common themes of meaning; it cannot be inferred, however, that such themes are common to all young newly married couples who experience cancer. The credibility of the research would be enhanced by further exploration of the research topic, so as to provide greater illumination of a

relatively unknown research phenomenon.

One of the paradoxes of the narrative turn is its claim to provide a systematic way of exploring research data in a way that simultaneously attends to the uniqueness of personal detail and the universality of common themes. It would seem axiomatic that this "best of both worlds" expectation must in some measure fail; however, in looking back over the analytic process and results, it seems to the researcher that the goal would have been more fully attained if more experiential detail had been included.

An interesting limitation of narrative research which is particularly applicable to illness studies is the question of embodiment. Frank (1995), Kleinman (1988), and Radley (1997) are some of the writers who have emphasized the need to understand the illness narrative as an expression of bodily experience; as Toombs (1992) notes, "illness manifests essentially as a disruption of lived body" (p. 62). Narratives such as those in this study, however, can fail to embrace this understanding. Interview questions that addressed the meaning of the cancer experience as an embodied process might have contributed more depth to the results.

The application of the findings in this study to other patient populations is also limited by diagnostic heterogeneity, in that three out of the marriages studied involved the wife as affected person, and those three all involved a female-specific type of cancer. The study's findings could have been strengthened if the recruitment process had produced a greater number of husband-affected couples and a wider range of cancer types.

In counterpoint to the above, it could be argued that any research findings from a sample of mixed-diagnosis participants are invalid. Can a couple dealing with breast cancer really be compared to a couple dealing with skin cancer? Some of the inconsistencies in narrative theme in this study might be attributed to the admixture of cancer types.

Another weakness of the "mixed" cancer study is that it does not allow for the collection of information on the relationship between the specific diagnosis and the psychological effects of that diagnosis. If the illness variable had been coincident, the diagnosis itself could have been

investigated as a possible causal factor in the participants' reactive stances to their cancer experience.

It must also be observed that the participants in this study, though all had been diagnosed with cancer within the first three years of their marriage, were not interviewed at the same point in time relative to their cancer experience proper (i.e. diagnosis and treatment). Thus, since various amounts of time had elapsed since that experience, the couples studied were in different stages of their transition through the experience. It can be expected that such a variance in elapsed time might affect such factors as degree and accuracy of recall, tone and content of presentation, and configuration of meaning.

This study is also limited by the absence of cultural diversity. All of the participants were Caucasian, heterosexual, and upper middle class, resulting in a high degree of demographic heterogeneity. The experience of cancer is undoubtedly affected by cultural perspectives, but it was not possible to explore this issue in the study.

Finally, it must be observed that such point-in-time studies as this cannot hope to capture the full range of meanings that will ultimately be ascribed to the cancer experience by the couples in this study. The construction of meaning is a dynamic process, especially when it involves such an uncertain phenomenon such as cancer, with its inevitable threat of recurrence. The meanings discussed in this study, therefore, are merely fleeting imprints in a meaning-making journey that started before this inquiry and will continue long after it.

The Researcher's Experience

As I have worked with many people struggling with the cancer experience, I have a certain amount of experience with the concerns that arise. In fact, I was working directly with such people, in both the practicum setting and through volunteer work, as I prepared this study. The participants in this study, however, shared some of the most poignant stories I have ever heard.

In being aware of my own process, it was important for me to realize that my sense of this poignancy was informed not just by the content and presentation of the stories but by my own life

experiences. Three of my closest friends have had their young adult lives transformed by cancer, and two of those succumbed to the disease in my presence. This kind of personal connection to one's subject matter can, of course, present problems, but it can also make true connection and understanding possible and thereby enable a more accurate representation of the research data.

It is my belief that compassion is the single most important therapeutic characteristic of the cancer caregiver, and that without compassion a clinician has no basis of understanding or empathy. It also seems necessary to have a deep sense of humility, in order to appreciate that we can lend our strength, knowledge, and support to others but in the end they must rely on their own resources to get where they need to go. In my research process I was gratified with how well the narrative orientation supported the goals of compassion and humility.

Finally, I must acknowledge a personal debt to the qualitative research process, which allowed me to achieve a considerable level of awareness about my own ascribed meanings of illness, cancer, suffering, and mortality. It is hoped that this will lead to a deeper appreciation of my future clients' own struggles with meaning and a more profound connectedness with the humanity that we all share.

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APPENDIX A: RECRUITMENT NOTICE

I am a Masters student in the Department of Counselling Psychology at the University of British Columbia. I am conducting research to study the meaning of cancer in a new marriage. The faculty advisor for this project is Dr. Larry Cochrane.

Participation in this study will involve 2 interviews lasting from 1.5 to 3 hours. I am seeking participants who have experienced cancer in their marriage through the diagnosis and treatment of one spouse, and who are now in a post-diagnosis phase. At the time of the diagnosis, the participants will each have been 35 years of age or less and have been married for no more than 3 years.

Interviews will be taped on audiotape. To ensure confidentiality tapes will be given a number code, will be kept in a locked room, and will be erased upon completion of the study. Names will be changed in all written accounts of the study and in the final thesis. Participation is entirely voluntary and participants may withdraw at any time.

It is hoped that by participating in this study, participants will contribute to helping others who may face similar experiences.

FOR FURTHER INFORMATION PLEASE CONTACT:

Marilyn Barz
(phone number)

APPENDIX B: PARTICIPANT CONSENT FORM

TITLE OF THESIS: The Meaning of Cancer in a New Marriage
RESEARCHER: Marilyn Barz, BA, LLB, Masters candidate (UBC)
FACULTY ADVISOR: Dr. Larry Cochrane

This study is being conducted to gather research data for the researcher's graduate thesis in Counselling Psychology at the University of British Columbia. The purpose of the study is to understand the impact and meaning that the experience of cancer has for a new marriage.

Participants are volunteers who agree to attend 2 private interviews with the researcher. In the first interview, the couple's story of what cancer meant and continues to mean within the context of their marriage will be sought. In the second interview, the researcher will present the couple with a written summary of their story to ensure that it is accurate. The 2 interviews will last 1.5 to 3 hours each, and will be conducted in a mutually agreed-upon location. The interviews will be taped on audiotape.

All contents of the tapes and identities of the participants will remain strictly confidential: tapes and research notes will be kept in a locked room, codes will be used in place of names, and computer files will be accessible through a password known only to the researcher. The researcher will be available before, during, and after the interviews to answer any participant questions and to ensure that all procedures are fully understood. All tapes will be erased and research notes destroyed upon completion of the study. In the thesis, names will be changed to protect the participants' privacy.

Any participant may refuse to participate or withdraw from the study at any time without jeopardy. Participants will not receive any monetary compensation. Any participant who has any concerns about his/her rights or treatment as a research participant may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration, at 822-8598.

I CONSENT to participate in this study and acknowledge receiving a copy of this consent form.

Name _____ Date _____

APPENDIX C: INTERVIEW PROTOCOL

The following questions were used in the first research interview:

1. Could you tell me about your experience of the cancer diagnosis?
2. How did you as a couple experience the period of treatment?
3. What were some of your feelings and thoughts about the cancer itself?
4. What kinds of things helped you get through the difficult times?
5. What was it like for you to experience this so early in your marriage?
6. Can I ask you a bit about some of the changes you experienced?
7. What is different or unique about your relationship now?
8. How has this experience affected your views of the future?
9. How has this experience affected the way you relate to each other?
10. What has the experience of cancer meant to you as a couple?
11. Why do you think cancer happened to you?

APPENDIX D: SAMPLE TRANSCRIPT

This transcript is one of four prepared for this study. The letter R is used to refer to the researcher. The names of all people referred to, as well as a few identifying details, have been changed to protect anonymity and confidentiality.

FIRST INTERVIEW

R: I'd like to go over the purpose for this interview and what you can expect during its course. As you know, I'm researching the meaning of cancer for young married couples. To accomplish this I'd like to ask you a series of questions that I hope will encourage you to tell me the story of what this experience has meant to you and your marriage. Are you both comfortable with that?

Brad: Guess so, sure.

Ellen: Sure.

R: Great. I think what would work best would be to ask you to talk a bit about how you met, when you got married, any important events in your early marriage, and then talk about the cancer diagnosis. Would that be OK?

Brad: Yeah.

Ellen: (nods)

R: OK, great. First then, how...how did you meet, and when did you get married?

Ellen: Well...you won't believe this but...we met through a personals ad.

R: Oh, yeah.

Brad: It was MY ad.

R: Uh-huh...

Brad: Yeah, I though, 'Why not, what've I got to lose?'...so I caller her up...I think she was, uh, third on the list or something...can't remember...but there were some common interests so I thought, OK...it was just a casual thing...

Ellen: Yeah, just casual, hiking stuff, dinner...just casual...he was busy at work, travelling quite a bit...

R: Uh-huh...

Brad: But eventually...I guess we met in '91...

Ellen: Yeah...

Brad: ...but eventually, we started spending more time together, off and on...I liked the way she liked science stuff...motors, bikes, stuff like that...I'm a mechanic, so...

R: Oh, yeah?

Brad: ...yeah...so we'd work on my bike sometime, she'd get all micked, mucked up...kind of different, I thought...I'd bug her, bug her a lot (laughs)...'hey, baby, what's happened to your make-up?' (laughs)...

Ellen: Yeah, he'd bug me that I was a 'biker chick'...I wanted to kill him sometimes...it was like, lots of women do stuff like this, what's the big deal?...

Brad (laughs): Yeah, she called me 'The Slammer' cause I was always...buggin' her...slammin' her and her family, you know?

Ellen: (laughs) You just hung around men all the time, that's all...

Brad: Well, you kinda liked that when we fixed your truck!

Ellen: Yeah...

R: So you started seeing more of each other...

Ellen: Yeah, and eventually I moved in...we lived pretty close to each other, in Town A and Town B...he had this big old house, like an old prairie house...it was pretty weird (shrugs)...

Brad: You're makin' it sound like we just met each other and bam! boom! we were livin'

together...don't forget we kinda broke up a few times...couldn't stand each other for too long!

Ellen: It was a bit rocky, yeah...

R: So you lived together, then decided to get married...?

Ellen: Yeah...we were in Mazatlan and...he proposed, like out of the blue...it was nothing planned...I thought 'What? What is going on here?'...it was so...unexpected...crazy guy!

Brad: Kind of the margarita thing, I think (laughs)...could never figure out that tequila effect thing...

Ellen: (laughs)...you always blame it on the tequila...

Brad: (laughs)...I blame EVERYTHING on tequila!...

R: Then you were married...?

Brad: Yeah, in '95, big bash, '50s music...not your usual wedding...

Ellen: Not your usual wedding is right...my parents couldn't believe it...

Brad: It was cool...we had my friends playin' live music on the deck...Ellen's mom and her cronies did all the cooking...the best Ukrainian food you ever had in your life!...we rented one of them big lawn pools (laughs)...everyone got dunked at some time or other...and there was a real neat bar, an old car, friend's a paint shop guy, brought over his old Pontiac and made a bar out of it...couldn't believe a wedding could be so much fun...course it was pretty cas[ual]...pretty cas[ual]...

Ellen: We kinda liked that...no big church thing or ceremony...I didn't want some ridiculous 'do you obey, do you cherish' thing...not my style...no way...don't see why people always cry at weddings, maybe because it's so ridiculous, all that pomp and circumstance...you should be laughing instead of crying!...

R: It sounds fantastic...you obviously had a wonderful time...what was your early marriage like?

Brad: Rough! (laughs)...she started puttin' the screws on...(Ellen hits him playfully)...no, no, it was OK...quite a bit of, uh, back-and-forth, conflict...we're both, uh, strong people, opinionated, stubborn, little bit crazy...so lots of arguing, yelling, in each other's face all the time...couldn't figure out what the hell she wanted most of the time!...still can't (laughs)...

Ellen: It wasn't so bad...he'd been used to living alone...such a slob...and he had a lot of animals, pets, a lotta work around them besides his day-to-day job...I don't know, it seemed like there wasn't much time...there was always so much to get done, take care of around the place...

Brad: Yeah, well, you had all YOUR stuff, too...work and your family...all that art stuff, with the painting and kiln and...it was...like two giant...operations coming together...

Ellen: yeah.....so there didn't seem like enough time ever...what's it like for people with kids, God...so we used to get on each other's nerves, probably because we we trying to do so much all the time...but that's good, too, cause we...it was always interesting that we had so much going on, not the same stuff, different stuff, and some of the same stuff, too...and that was OK, that was good...lots of couples don't do that...

R: Sounds like you were very busy...um, how would you describe your relationship in those early years? From a...communication standpoint, a...togetherness perspective...?

Brad: We didn't have time!...no...it was good...we'd fight, but there was lots of...interest...challenge...fireworks!...Ellen was not anything like other women I'd known...(chuckles)...I sure as hell knew THAT...yeah...wow, I found THAT out!...she was tough...wouldn't give an inch...those Ukrainians!...her sister Laura was even worse, always on my case...couldn't do nothin' right...but so OK, I said to myself, I have to make some adjustments I guess, like fine tuning a motor, getting it better and better...my first wife was such a sweet little creature compared to Ellen...after awhile, they say, you know what you want, but...I don't know, I got more than I bargained for...

Ellen: That's true both ways!...very true both ways...anyway, like he says, I'm not the typical little wifey type...after all, we both had our own lives before...we just had to lump them both together and then try to make them fit...try to make the families fit together, get used to being a married couple, which is different than living together...

R: How so?

Ellen:...um...it's the heavy slogging...the living together is, like, fun, silly, not serious...I mean, we

were serious, but it was different...um...I guess it just seemed suddenly that we weren't just two big kids having this good time...taking off for a trip, just getting away...now we had to consider our families, and the future...money and stuff...talk about stuff seriously...but I don't think we wanted to give up the old way of doing things, living together like a new couple...

Brad: I sure didn't...I was thinking 'What the hell did I get myself into?'...goddamn tequila (laughs)...I probably made it harder, I was buggin' her all the time...she'd get her back up right away...it was so funny...sometimes I was just buggin' her, didn't mean anything by it, but she'd get her back up and wham!...there we were goin' at it tooth and nail...

Ellen: Yeah, don't you remember that big fight about the house?

Brad: What about the house?

Ellen: Where you said I could choose between paying rent or starting to pay into the equity?

Brad: Yeah...was that a big fight?

Ellen: Yeah!...oh, that went on for days...weeks...it was major...

Brad: Well, you were so damned scared of being in one place for any length of time...still are!...

Ellen: No, I just wanted to work out a fair thing...not be in a position that wasn't right...for you OR me...

Brad: Well, it was all pretty stupid...you were not thinkin' clearly...but, yeah, I guess it was a major deal...and then the family thing...her family was not particularly thrilled with me, who knows why, or should I say let me count the ways!...

Ellen: Well...it was my first marriage, and Brad had been married before...that didn't sit well...my family's very traditional, very old-fashioned...kinda old world...they were a bit funny about that...plus Brad's very outspoken, doesn't think before he speaks...some things were said that were...maybe too soon to be said, I don't know...things that would have been better left unsaid...I don't blame Brad, he was just being himself, but my family's more...formal...inhibited...I thought that was obvious and Brad should've known that...

Brad: Ah, they're just a bunch of tightasses!... You know it's true...

Ellen: (silently rolls her eyes and sighs)

R: Tell me, how...how were you able to work through all that stuff?

Ellen: We haven't! (smiles)...no, not really...I guess when they found out how helpful Brad was...he was always doing something for them...building that shed...and that time the car had that oil leak...remember you fixed that for my dad...yeah...well, they got a bit warmer towards him then...I didn't really care anyway what they thought, I married him not them...

R: Right...let me ask you..what do you think was the, the biggest challenge you faced in your early married years, as a couple I mean?

Ellen: It was probably the kids thing...

Brad: Can't argue with you there...

Ellen: We had to...Brad's always wanted kids, and I've never wanted any...I don't know, it...I've just never seen it...just never had the urge...of course my mom and dad have always wanted grandkids...see, there's three of us girls and my one sister is not married and the other...well...we won't be seeing any grandkids there...in other words, there's no kids in sight from any of us...so they...they're probably thinking, OK, when are Brad and Ellen going to start having kids?...probably started thinking that at the wedding!...little did they know, we were having these ENDLESS arguments about it, nearly breaking up over it...

Brad: Yeah...I've always wanted kids...guess that's why I have so many animals...my brother and sister have kids so at least I'm an uncle...but, you know, it's so weird, my first wife said she wanted kids when I married her and then everything changed...I don't know what happened there...it was, it was rough...I guess Ellen and I discussed it before we were married, didn't we?...

Ellen: ...yeah, we did, we did...

Brad: ...but nothing was decided, I remember she was kinda lukewarm about it but not completely against it...

Ellen: I can't remember a day when I've ever been lukewarm about it, but there you go, wishful

thinking on his part...

Brad: I don't think so (sighs deeply)...but then we got married and I'm thinkin', OK, we'll talk about this, most women have that biological clock thing goin'...I thought, let's do some serious talking about this, so when we finally did, and then I find out she's dead against it...I thought, geez, what is going on, what's this all about?...so we hashed it over, probably over a month or two, really goin' at it...basically it's a no go, dead in the water deal...and I'm feelin' 'you bitch!', you led me on'...that's how it looked to me...

Ellen: So not true...as I say, wishful thinking, big time...

Brad: Yeah right...anyway, when it comes right down to it you can't do anything about it, you can't justify making a woman being a mother...well, you can't do that anyway...I mean, I went through it with my first wife and struck out so I'm used to it (laughs)...it's like, why do I always get involved with these women?

Ellen: I said to him, you're gonna have to live with it, and I think when he finally realized that was the way it was gonna be, he was mad all over again...I mean, first he was mad at me cause I didn't want kids, and then he was mad at me...mad at the world...once he told me 'This is a dealbreaker!', like if I didn't want kids he didn't want to stay married...like the marriage was some sort of 'deal'...gee...it was a rough time...it felt like we were in crisis mode for months...fighting, fighting, fighting...not even sleeping in the same room sometimes...can you imagine, this is real soon after our wedding...well, not long after anyway...

R: So...what finally allowed you to come together and...um...stay together as a couple, after everything that had happened?

Ellen: Well, I think one night Brad had this long talk with his brother...remember?...you came home and you had flowers and I was glazing that penguin and you said you were sorry, could we just go out to dinner...like we used to, and...

Brad: I don't know, I can't remember what my brother said...maybe it was my sister, she can usually bully me into things...

Ellen: No...it was your brother...you said he took a stripe off of you...so, yeah...we went out, I was so tired of all the fighting and being apart and feeling like, wow, how can this be happening, breaking up already, we've hardly been together yet...so we went to Restaurant A, it was different somehow...it was like we were all deflated, all...tired, I guess...

Brad: Yeah, but it was better than fighting...

Ellen: Yeah...so we talked, and it wasn't easy, I thought he was such a jerk for pressuring me and ignoring my wishes...I never said I wanted to have kids...I never 'led him on'...but we'd taken so much out of...the marriage...by all the fighting...in fact I thought 'Can we ever ever get back to where we were before?'...but...well...I guess eventually we did...no, first we had a truce, like a moratorium on fighting!...then I had to get over resenting him so much for all the pressuring me...that wasn't easy...and he thought I'd misled him which was just not true...so not true...but...finally we realized, I guess, that we were going to go on regardless...

Brad: Yeah...I think that's when we took that camping trip to Mountain A...it was like we'd been through a war or something, and, and we were the survivors, the veterans of the big one...almost like, OK, we've come out of this, we're both still standing, we're both tough as nails, now where do we go from here...

Ellen: We got it all out of our system, I guess, cause we didn't fight at all that whole trip...in fact it was kinda like a honeymoon, second honeymoon...sounds kinda goofy...I felt good that I hadn't given in, think maybe Brad knew from then on that he wasn't going to have any...power over me, couldn't push me around, he's a big guy and he likes to have his way, likes to be the tough guy, the guy in charge...I guess maybe that worked sometime with other women, but it wasn't gonna work with me...

R: Mmm...can I ask you, sort of in light of what you've been talking about...um, how do you each view marriage during this time, what to you was the meaning of your marriage, the reason for being married... what did it mean to you?

Ellen: (long pause) I guess it's an expression of love...a commitment...a bond that says to the world that you're serious about the relationship, you want it to be a lasting, forever kind of thing...but also a partnership, like in business where you each keep your...independence...where you don't have to change for the other person...

R: Mm-hmm...Brad?

Brad: (sighs)...It's been different things at different times...

R: Such as...?

Brad: Well...way back when, I got married and it was probably for sex (laughs)...well, that's probably not fair...but still, I wanted sex and kids, I know that...didn't think about much else...

R: And now?

Brad: Now it's more about personality...do I like this person...can I have fun with this person...is this person kind of in my corner...is this gonna be an adventure, is this gonna be a challenge...but not so much of a challenge that it's not fun...

R: Right...(reflective pause)...I want to thank you for sharing those memories and thoughts with me...it gives me a wonderful picture of the two of you...of your marriage and how it was before the cancer came into your life...perhaps we can turn our attention now to the next phase, the cancer experience...I'd...can I ask you to tell me a little bit about the experience of the cancer diagnosis...how you came to receive the diagnosis, what impact it had on you as a couple...

Ellen: I found the lump in my breast in the shower...it was in March, just after my birthday...it was like all of a sudden I was ice cold, in the middle of the hot shower...I just stood there, just frozen...I told my sister the next day, we were at the tile store, she was getting new bathroom tiles, I told her in the car afterward...she said 'What did the doctor say?', I said I hadn't been yet...I guess I went the next week...it's true, your whole world changes, turns upside down...I knew it was cancer, I somehow knew it was...(sighs)...I was not impressed by the doctor...oh, he seemed to know what he was doing but he hummed and hawed and just...just tell me, stop beating around the bush!...and then I was out of there, no chance to ask any questions or ask about books and stuff...I don't know how I got through that week, I don't remember much of it, just not sleeping, not eating, only my sister knew, it was horrible, horrible...not knowing is just torture...I told Brad I was worried about work, we were moving my department so it was a good excuse...I drank a lot, even during the day...sometimes I'd get up in the middle of the night and have a drink...we have this one dog, and he knew, I can't explain it but he was always nuzzling me, sticking by my side, sticking his nose into my lap...if I cried he'd come over and sit looking at me with these big goofy eyes...so...anyway...I had the test, it was positive, it was a fairly large tumor but not too terribly aggressive so I was lucky that way...and also it hadn't spread...I remember my sister and I celebrated the 'good news'...ha ha...with a big sushi lunch, lots of sake, more sake than shushi...I mean sushi...yeah...what a shock, and yet...could have been worse...

R: What a...difficult time that must have been...yeah...Brad, can you tell me...um...about how Ellen shared the diagnosis with you, how you felt about the diagnosis?

Brad: (sighs deeply)...I'd come home from work and Ellen was there...normally she gets home later so I thought maybe she left early or was sick or something...I was just bowled over when she told me...I remember I was mad that she hadn't told me about what was happening earlier...I guess I was mad, I don't know at what...I asked her what they were gonna do, she started crying, she...she couldn't talk...I think she couldn't bring herself to say 'mastectomy'...she never actually said the word...well, we talked a bit about what would happen next, it was all set up...

Ellen: It was going to happen soon, yes...Brad's right, there was something about the word 'mastectomy' that was too final to say...it was very hard telling Brad...I wasn't sure what he would do...I just blurted it out, I think...I didn't know what the whole thing would mean for us, the marriage...I was in the middle of a big shift at work, it was a major deal but obviously I'd need time off now...

Brad: I told her not to worry about the work thing, she had to concentrate on the other stuff now...who cares about the work thing...

Ellen: Yeah, but that's easier said than done...my job is really important to me...lots of responsibility...it was such bad timing...

R: Mm-hmm...I'm wondering...what are some of the...other thoughts that went through your minds? About the cancer itself, what that meant?

Brad: It was tough...I tried not to think about anything negative, but of course you can't help it...I didn't know anything about breast cancer, it was all a big mystery...I knew what a mastectomy was, and I asked why it had to be so drastic...Ellen explained about her cancer, explained about the surgery and the rest of it, the radiation, yipes I thought, what's that gonna do to you physically, what's gonna happen, she explained a bit about it, I couldn't really grasp it, I had no idea what to expect, in a way I felt like running away...it was just so unexpected, such a shock...just so out of my league, I mean my mom and dad had had health problems but not cancer, I couldn't believe it, Ellen was so active, ate really well, healthy family...couldn't believe it...I remember we drank a lot of wine, had some McDonalds's...

Ellen: Yeah...what a night...no, we ordered a pizza...but you're right about the wine...we talked about how we had to tell the families and how it was going to be so hard on my mom...we're kind of tough, hardy stock, hardly ever sick, my grandparents lived into their 90s...I remember when we were lying in bed, how I wondered why Brad just went to sleep...

Brad: Did I?

Ellen: Yeah...I remember thinking that it would be nice to...well, I don't know what I expected, really...but I just lay there, sort of immobile, I guess maybe immobilized by fear, wondering what would happen...with me, with us...

R: Yes...it was hard to take in...such a shock all at once...and then I guess you started your treatment...can you tell me how the two of you as a couple experienced that period, the period of treatment?

Ellen: I had to take time off work...I'd told my family, and we all cried...and we don't cry easy!...Brad was having a hard time dealing with everything...I could tell...it was hard...my sisters were great, helped me get through the surgery and the radiation...the worst part of it was the radiation, it was so awful...Brad was trying to be supportive, he'd make me special drinks and give me massages, foot massages, rub my temples...but we didn't really talk through that time...I felt like I wanted my sisters around me, somehow, but that men wouldn't understand...my mom was a bit hysterical at first, I wished she'd just go home...couldn't deal with it...I think Brad and her had a few run-ins...I couldn't stand the littlest things, everything just made me crazy...

Brad: Her mother was a pain in the ass...she'd come over and wring her hands and look all down in the mouth, like it was a death watch or something...I shut her up a few times...told her to go home...it was a scene...anyway, I was super busy, all the animals and my job and doing stuff around the house...I was frustrated because it all seemed so out of my hands...angry at people who I had no reason to be mad at...Ellen was great, so calm and collected, got through it all like a trooper...

Ellen: I don't think you allow yourself to be OTHER than calm and collected...you just can't fall apart...well, I mean I cried a lot after the diagnosis, but not actually during the actual treatment...I was on coping alert...maybe the body knows you need energy to take the treatment so you don't cry...(sighs deeply, becomes slightly tearful)...but then...you have to face it, later...the after the surgery part...whew!...(long pause)...I can't talk about it even now...

R: Please don't feel you have to talk about it...it's OK, Ellen...let's move on to...Brad, what did Ellen's surgery mean to you...did it change...things... anything for you?

Brad: Well...it was shocking...I mean, the physical after-effect is shocking...we've talked about it since then so I know it's OK to talk about it...but I really didn't know what to say...what would be the right thing?...I kept trying to think 'What if I had something just cut off me?'...how does a person deal with that?...I couldn't fathom it...I know I felt so horrible about it and horrible about what it must be like for her...but I also knew I couldn't possibly understand...I'm glad she had her sisters...(long pause)...well, sure I wish it hadn't happened, and no one likes to have to deal with it, that's a given...but it had to be dealt with, and I thought 'If this is hard for me what's it like for

Ellen?'...

R: Yes...mm-hmm...

Ellen: The thing about it is...the thing about Brad is, he's pretty honest about things, sometimes way too honest, shoots from the hip like John Wayne, you know?...he didn't try to make it better than it was, sweeten things up for me...he was honest about how horrible he thought it was...in the end I think that I appreciated his honesty, but it was hard to take, like always with him...it's hard to take at first, but it's the way he is and in a way...it's better than trying to deny things...

Brad: Well, we've always been honest with each other...we'd always shout and scream and say what we thought...maybe not so much at the time, the time during the treatment...but we were honest about things generally...I told Ellen how I thought it was...just horrible, no use denying it...

Ellen: I had my family trying to cheer me up, that was the one side of things...'Oh, it's terrible but now it's over and you're going to be OK and everything will go on just like before and it's not like it's the end of the world'...(combination of sigh and chuckle)...I needed that...Laura and Teresa were great, they kept it so together...but Brad, he was like the contrast to that...he got mad and got angry, let it all hang out...that was good, too, that attitude balanced off the other stuff...I needed both, I guess...

R: Mm-hmm (pause)...Thank you both for sharing that with me...I know it's hard...I'm wondering if we can spend just a little time now talking about the cancer itself...what were your thoughts about it, how did you visualize it...imagine the cancer in your mind, the cancer as a thing?

Ellen: Well, it used to mean something that somebody else got...it's funny, when it's you it's so different...everywhere I looked, every magazine had an article about cancer, every TV show was talking about cancer...I wondered why everyone knew so much and I wasn't doing that for myself...I probably blamed Brad, wasn't he supposed to be doing that?...anyway, it was 'cancer cancer cancer', everywhere you looked...eventually I could hear the word itself without feeling kinda sick, or really cold...I guess for me it meant the end of 'my former life' (small chuckle)...it'll never come back...but OK, you gotta accept things...my surgeon was OK, told me about some of his other patients, support groups, I met a few people and talked to them, that was good...so I'm thinking now 'cancer' is just a word, it's not this big scary monster...but at the time it was hard to even get past that...

R: Brad...what kinds of thoughts did you have about the cancer itself? How did you...envision it?

Brad: Like Ellen says, it's just a word...but at one point, when it all happened, cancer had all the power...we were both living in its power...I mean in different ways, but it had us by the throat all right...

R: And what helped you as a couple to get to that point, to the point where YOU had the power...took back the power over the cancer...

Ellen: I think it was a separate thing...I mean, I had to see myself as being in control of what happened, and I did that, I think...I never really felt like I didn't have some control...

Brad: We got the power back when we refused to be out of our minds with fear...we're not scared people...we're both very...tough and do-things kind of people, grab that cancer with both hands and wrestle it to the ground!...it's something we really have in common...

R: Yeah...I can see that...I wonder if there were other things that got you through...I know you talked about honesty earlier...um...what other kinds of things helped you survive this experience as a couple?

Brad: I guess we should mention our, uh, bizarre sense of humour, eh Ellen?

Ellen: You mean YOUR bizarre sense of humor...

Brad: Very funny...make me look bad in front of her, go ahead...

Ellen: Yeah, well...

Brad: I seem to recall a certain incident in the hospital...?

Ellen: You're on thin ice, Brad!

Brad: Hey, it's not that bad...what happened was, Ellen went to this class, something new age, and I was meeting her afterwards, it was just before Halloween, so I thought I'd surprise her by wearing

my Halloween costume from the year before, which just happened to be an accident victim...so I walk into the lobby all covered in gore, fake eyeball thing, gashes and scars and blood, the whole nine yards...people were screaming, I just about peed myself...

Ellen: (sighs in exasperation)

Brad: Hey, come on...it was a blast!

Ellen: Right...

R: That's quite a story, Brad...aside from this...incredible sense of humor, was...was this something you shared, Ellen?...the humour aspect...

E: Oh, sure...Brad could always make me laugh...but...sometimes he's...just crazy...

R: Were there any other things...what other particular strengths in your marriage or outside things did you draw upon?

Ellen: I guess that's about it...well no, my family...well, really, my SISTERS...they were great...took me to all my appointments, brought food over...they were there, a rock...yeah, Laura and Teresa were amazing...they took the time, they were always ready, always there...and they really kept the mood up, 'cause it's not like we were exactly feelin' down or suicidal or anything but still...they kept everything positive...

Brad: Yeah, they were great...great...I never really got along with them all that well...especially Laura...you know, the in-law thing...but I gotta say they took care of Ellen, took charge, got it all done...

R: Mm-hmm...anything else, things about the two of you that made the experience bearable, even perhaps...a positive experience?

Brad: Well...we've always had this...strong physical attraction for each other...right from the start...it was probably what kept us going...we used to have a big fight, then make up...it wasn't just sex, don't get me wrong...it was a chemistry, attraction of alikes, I guess...feudin' and fightin' and makin' up...well, of course that kinda stuff was a no-go during the cancer, things were very different...but I never thought that attraction was GONE...I thought it was still there...might have been different from Ellen's...you know, she was pretty weak, and tryin' to deal with it all...

Ellen: ...Yeah...when I had the surgery, I was worried...what was going to happen to that...that thing Brad's talking about...it wasn't number one in my mind but anyway, it worried me...I remember thinking that he asked to see my scar and I thought, 'I'll be able to tell by his face how he feels'...but then I couldn't really tell...he didn't really react very much at first...

Brad: I didn't know what to do...how was I supposed to react...she'd just gone through surgery, I want her to feel it's OK but I can't just throw myself on her...or should I throw myself on her?...do I WANT to throw myself on her? (chuckles)...God, what do you do?...it looked so horrible...finally I just said exactly what I thought, told her it wasn't a pretty sight, but it's OK, it'll heal up...

Ellen: He just said what he thought...and he seemed so upset at what the surgery had done to me, that was kind of...sweet...I appreciated that...I felt the same way but I was supposed to be so upbeat about it all...well, I wasn't, it wasn't OK...and Brad just said that right out loud...and it hurt but it was true...

R: So you appreciated it...yeah...so...it sounds like it was very difficult...trying to accept this difference....

Ellen: Well, in a way I felt like an alien in my own body, it was terrible...so who'd want to even think about sex or anything like that...and I was also very tired, and my body felt very sensitive, so it wasn't very good...it was uncomfortable...I didn't want to be touched too much as I recall...we were trying to be like ourselves, I mean like the ourselves from before, but we weren't, we couldn't...

Brad: We were very physical before, probably more than other people...I mean, uh...we were very active, you could say athletic (laughs)...uh, Ellen's a strong woman, not just physically but...she asserts herself, she's not afraid to be like that...

Ellen: Yeah, and here I was this weakling, I'd lost weight, no muscles like before, I was always toned...but...oh, I was so mixed up...I wasn't really me...so...I was happy that Brad made the effort, I guess, but it wasn't any good, it wasn't like before...I thought, this is so terrible, so lame, maybe I

should tell Brad he should find someone else...I'm holding him back, why should he go through this pathetic exercise to make me feel better...

Brad: I didn't know it was so bad...well, I knew it wasn't no porno scene (laughs)...but...well...it got better...didn't it?

Ellen: It was quite a while...I think we were both scared...shocked by how different it was, yet we were really not different people at all...I know I was scared...I thought 'If this is the way it's going to be, no thanks'...but then, I started feeling better, and not so sick and tired all the time...and at some point I went back to work, just part time...but I know that was a good...a good thing for me, made me feel like I'd maybe come through this thing...this nightmare...and I was talking to the other women, and one of them said something I thought 'What?'...she said the sex was actually better afterwards...wow, I thought, OK...

Brad: Yeah, when you went back to work things changed...I felt, OK, you're stronger, I don't have to be the Rock of Gibraltar all the time...I stopped thinking you were sick...it was closer to the old Ellen...yeah, it was like you were yourself again...

Ellen: Yeah, but...I really wasn't...I had this appearance of the old Ellen...but inside I think it was actually hitting me for the first time, in a way...I tried to show a good face to the outside world...everyone had been looking after me, putting themselves out, changing their lives around, catering to my every need...but at work I felt spaced out...like a post-partum depression thing maybe...yeah...so everything looked like normal, back to the old way, she's a cancer SURVIVOR now, YAY!...but inside I was just so numb, depressed...and I couldn't call on anyone, they'd done so much already...I drank a lot, I think...I...drank too much...yeah...

Brad: You know, it's weird...you seemed so OK...I thought things were good...I was out with the animals a lot, playing sports, doing some woodworking...thought things were getting back to normal...it was more normal, but I guess it was still weird, in a way...it was normal but it was different...

Ellen: It WAS a weird time...I got some medication, anti-depressants...that didn't help...so I went on a retreat...my friend Anne suggested it...it was very useful...a retreat for people in recovery, recovery of any kind...I met some people there that were in such worse straits than me...I remember I came back and went into the kitchen and just wrapped my arms around Brad...(long pause)...

Brad: Yeah...

Ellen: It was one of those moments...sounds like a movie, something with Meryl Streep!...yeah, so...I realized I was a very lucky woman, I saw things in perspective...at the retreat we all kept a gratitude journal, it was a very helpful thing...that moment, standing there holding Brad, I felt...like my life was OK, that yes, me and Brad were going to be OK, we were still a couple...I let myself accept that, I guess...why I couldn't accept it before I don't know but I guess I wasn't ready...

Brad: (laughs) I thought 'OK, what's going on?'...but that's when we sort of got back to normal, having sex again...it was GOOOOD sex!

Ellen: Brad...please!

R: Well...thank you both for that...so...let's look at another aspect of this...I'm wondering...what was it like to experience this so early in your marriage, this experience of cancer which...usually would occur at a much later time in a marriage?

Ellen: It was devastating...a terrible shock...I mean, I was YOUNG...only 36...just turned 36...when I was diagnosed...that's not an age when you're expecting you'll get CANCER...or any disease like that...so, I mean...wow...what's going to happen to me, what's going to happen to my marriage, what's going to happen to my job?...we had such fun, in the early years of our marriage...we were still barreling along...why should that end so early?...we travelled a lot, went camping, had parties...lots of good times...and besides, I was young, my body was not an old body, and it was in shape, healthy...we were still young, well young for nowadays I mean...we were both in good shape, pretty good diet, took the vitamins and everything...now here I'm 36 and this is happening?... (shakes head)...

R: So you felt that 'this isn't right, this just shouldn't be happening'...

Ellen: Yeah...definitely...well, I realize anything can happen at any time...I mean, it CAN happen to you, I know that...but at the same time this can't be happening, too young, too healthy...it was an unreal experience...unreal...

R: Was it like that for you too, Brad, coming at such an early point in your marriage?

Brad: It was weird...I mean, all marriages have stuff to deal with...but I guess we thought it would be the usual stuff...but CANCER!...money, kids, Maybe...you know, the typical stuff...but even more than that...it's not like we were these sickly people, or junk food fanatics, or living next door to a Three Mile Island or something...we were kinda health nuts really...really active, swimming and hiking and sports...so is all that just crap, you know?...what's the point?...what is the fu...bleepin' point?...mmm...(shakes head)...

Ellen: And here's our parents, still doing OK...well, sure, some health problems, you know, but...doing OK otherwise...now my parents have to look after ME?...my mom was not prepared for that, not prepared at all...my dad, well...he's pretty even-tempered, just goes along with the flow...has to, to put up with mom...but I'm sure he was very worried, so worried about me, in his own low-key way...he's such a sweetie...

Brad: I thought your dad handled it just aces...he was aces...

Ellen: Yeah, I know...he's quite a guy, all right...

R: I'm curious...has this experience made any difference in...in how, how you relate to...how you fit in with...your friends, your age group?

Brad: (laughs) Oh, yeah...I mean, man...I'm going through this thing, this cancer thing, we're going through hell...and there's our friends...I mean, some were great, don't get me wrong...but I don't think they understood...it's like, normal friend relations went on, just like before, with me mostly, Ellen was in her treatment...but it seemed so...bizarre...they didn't know what we were going through, they couldn't...so I'm out drinkin' with the guys, I'll never forget this, I'm out drinkin'...and one of my friends tells this boob joke...I could not believe it...I laughed, I mean it was a FUNNY joke, but meanwhile here's my wife...can you believe it?...so...people are weird...I know they don't understand, but...

E: Of course they don't understand, how can you expect them to understand?...but that's OK...by and large everybody was OK...but it was weird...when I got well, started seeing my friends again and everything...I mean socially, like movies, going for lunch...it was weird, I could not figure it out...it felt like everybody...these are my girlfriends, you know...it felt like they were all looking to me for something all the time...like I was the new leader of the pack!...I'm the big cancer survivor, we have to give her the say-so first...hmmph!...anyway that went on for awhile, it's OK now, back to normal thank God...

R: Hmm...so what about...now...is there any difference...have there been any lasting effects in the way...the way you relate to your friends?

Brad: I feel older than them...they're great guys, it's part of their charm...but...no, everything's good, everything's OK...

Ellen: I always thought...Brad seemed different than his buddies...I noticed it when I met him...they're...he's more mature...well, as mature as Brad can get!...mmm...I guess it's probably a bit more pronounced now...

Brad: But you know she's always naggin' me that I'm too IMmature...crazy woman...make up your mind, woman!

R: (chuckles)...can I ask you about how...um...what kind of changes you have experienced as a couple because of this experience...how has this changed your marriage?

Brad: Wow...

Ellen: Yeah...wow...well, I guess for starters, I'd say that I feel it's stronger...yes, definitely stronger...

R: How so?

Ellen: We've been through this thing, and...we didn't really go through it together, more like separately...but when it was over there was a chance it could have gone either way...nobody's taken

lessons in how to get through cancer, let alone how to get through the aftermath...I guess we always had a bond...but something like cancer, it sort of supersedes other things...

Brad: Yeah, it's hard to describe...other couples who have been through this kind of thing would understand...I don't think WE really understand it!...

Ellen: Like...we don't sit around and analyze things, so we probably DON'T understand it...but I always felt that before, we were both so hard-headed and stubborn, we were looking out for ourselves more than for us as a couple...

Brad: I guess it wasn't surprising, we're both so independent...I always liked that in Ellen...then when she got the cancer I wanted to do something to help her or protect her but there wasn't much I could do...anyway, she's a tough cookie, I remember when I first tried to open a door for her she just about bit my head off...

Ellen: Yeah, whatever...Brad knew I was strong, but there's strong and then there's a STRONG...I couldn't have come through the surgery and the radiation like I did, if I didn't have some extra strength...Brad always saw himself as this big macho guy, he likes to lay on the 'protect the little woman' thing...I never let him get in the door with that stuff...but he wants to be protective of me now for different reasons, I think...but...so now he's protective of me as a strong woman, not protective of some pretty little thing...he might want to be with some helpless little thing, but maybe not so much anymore!...

Brad: Yeah...it's interesting...she was kind of helpless, in a sense...I mean, I guess we're all kind of helpless, have to depend on the doctors...but I never saw her as helpless and I don't think she did either...it was a test of strength, and a person can either pass the test or see themselves as helpless, I can't hack this, I give up...I...I never for a minute thought that Ellen would give up...if it's a test of strength, Ellen'll be in there givin' it her best...

R: Mm-hmm...are there any other ways things have changed for you as a couple?

Ellen: (pause) We have this...kind of slowed-down life...I mean, before, we were such go-getters...always on the go, camping, hiking, skeet shooting, trips...it was non-stop...now we aren't always rushing around, a million things at once...that was crazy, but fun...so...we enjoy quiet times, whereas before, it never occurred to us to HAVE quiet times...like for instance, last week we never went out once all week...just cooked dinner, saw some vids...

Brad: Yeah, it's cool...and I think I've...uh...streamlined my life, uh, we've both streamlined our lives...it's not so complicated...not so much stuff...

Ellen: That's true...we always had so much stuff around, projects, something was always on the go...it was like, my daybook was crammed, no spare time...always rushing around buying stuff, arranging things...doing my collages, my pottery...Brad with his sports and cars and bikes...and all the animals, looking after them...so much to do around the house, it's a big house, needs fixing up...it was so hectic...but we loved it, got a lot of energy from it...it was OK for that time I guess...

R: And now it's a different time...yes...and would you say...that things are different...have changed with...how you relate to each other as man and woman?

Brad: As man and wuh-man...whoa!...she's gettin' into the down and dirty stuff now (laughs)...yeah, baby!...

Ellen: We...we have found our way back, I would say...

Brad: Ellen was the one who had to be OK about...being OK with this way back thing...I guess women are more tuned in to these things...when she got back from the retreat it all sort of came together...it's like we stopped pushing it or something...

Ellen: Brad, I think that's exactly right...I know I was very tense, and then all of a sudden I wasn't...all of a sudden I felt glad to be alive, thankful that I was alive and doing OK...happy that you were still there, my job was still there, my family was all around me...it was like a big shadow was lifted off me...and that's not to say it's been easy, it hasn't...especially the fear it might come back...but I'm happy, and I couldn't imagine ever being happy again back when I was diagnosed...

R: It sounds like there's certainly been a change...speaking of change, what do you think is different or unique about your relationship?

Ellen: Probably nothing! (laughs)...hundreds, thousands of couples go through this...probably not so many who are as young as us!...so maybe that's unique, we are a young couple who had to deal with cancer...when we didn't expect it, or something like that for years to come...

R: Brad...?

Brad: I feel that we're unique...we're Super Couple! (both laugh)...I...other couples all think they're unique too...but we actually are!...well...I think we both know there's lots of strength there, in both of us individually and in the marriage too...it's good to know it's there, that we can count on it...

Ellen: Yeah...I think we feel different than some of our friends...their relationships are, like, settling in, some are good, some bad...but I wonder how much of a base there is...maybe that's what we have, a stronger base...

Brad: Well, if this cancer thing can't break us up, I guess NOTHING can...plus you just, as they say, 'see life differently'...all that stuff is true...I know I was angry about the kid thing, hadn't really accepted that, was angry at Ellen...yeah, that coulda broke us up...I'm OK about it now...maybe still a LITTLE pissed off!...but hey, that's life, I guess I'm stuck with her...

Ellen: It still isn't easy...we're still the same people...I felt like nothing would ever make that kid thing all right...like no matter how good life was, it wouldn't matter...to Brad...

Brad: That's true...

Ellen: So what could I do...

Brad: There was nothing you could do...but it all seems silly now, trivial...we've got lots of cats and dogs and birds and horses...

Ellen: Yeah, they're our kids...

R: Yes...may I ask you how this experience has changed your view of the future?

Ellen: It's a whole new picture for me...personally, I've really looked at what I'm doing, where I'm going...I'm going back to school next fall...I like my job, but...you know...

R: What about how things have changed regarding...your future as a couple?

Ellen: (laughs) You know, it's like the future is more secure, yet at the same time LESS secure...it's strange...I mean, I feel we're more secure in our marriage, but...and I feel more secure as a person, I think...but it's like, there's no safe, secure future anymore, anything could change at any time...yet that was true before!...so it's very strange...I guess...no...I don't know...how about, it's more meaningful when we plan now, because we know how easily it could all change...

Brad: Yeah...also we pay more attention to security things, like RRSPs, life insurance...also it's easy to discuss those things now, but before money was such a touchy subject for Ellen, such a crazy big deal...she's way more relaxed, calm, these days...doesn't think I'm trying some funny thing just because I want to discuss finances...I'm very practical, I like to go through things financially, know where I stand...Ellen was so weird about money, like her whole family...now, Ellen will talk about money like it's not the big taboo...

Ellen: It's better, yeah...now I also appreciate Brad's expertise in those things...I used to be so suspicious of it...just never wanted to listen, thought he had ulterior motives...I've always been kind of secretive about money matters, it runs in the family...I have no idea how my parents or my sisters are doing financially...they think all that stuff's a private matter...Brad's so not like that, plans everything about money, lays it all out...sensible, has all his RRSPs organized, investments, life insurance...I won't say I'm any financial whiz now, it still makes me nervous, but at least we're talking, I know where things are...know about the assets...gee, who is that talking? (laughs)...

Brad: Yeah, it's more like a marriage that way, like my mom and dad, everything was discussed, out on the table, my dad did the big stuff and my mom ran the household...money's no big deal as long as you think of it as a necessary evil and don't make such a big deal out of it...

Ellen: Yeah, I realize that Brad's actually...that talking about money is actually a sign of commitment...I used to think it was a sign of...he's trying to control me!...

Brad: Yeah, so I think we have a way better handle on the future now...moneywise I mean...we're also more conscious of having to save...I was always pretty good but Ellen was b-a-a-d...I like being able to talk to her about money stuff and she doesn't run away screaming...gotta keep her in

line, she's got no idea of what a dollar's worth...we'd be broke if I let her manage the money!...

Ellen: Probably...

R: What about other plans, like career, or how you think about work...what kinds of changes have there been?

Brad: We're both pretty happy in our jobs...no complaints...we haven't had to change much there...

Ellen: No, I like my job...but I'm going to take courses so I have more options...

R: What do you think has been the biggest or most suprising or most gratifying thing you've learned from this experience...I mean, learned as a couple...mmm...learned about your marriage?

Ellen: Well...I don't know...I guess we learned that...we're OK, we're doing OK...and the physical...your appearance and so on...and also the whole sex thing...is maybe not as important as I thought it was...well...it's important, but maybe it's not the biggest deal, the big thing between men and women like it's always portrayed...I thought, wow, our chemistry is so powerful, then I thought, well, now that's on hold, can't have much chemistry when you're going through that sort of thing, you're just struggling to survive, to get...get through the day, struggling not to give in to the fear or the depression or whatever...I'm not just talking about sexual chemistry, that's part of it but more like the energy...there was always a bit of a...conflict...push-pull type of thing...I say to-may-to he says to-mah-to, you know?...secretly I think we liked that even though sometimes we'd fight like cats and dogs...I hate that saying, our cats and dogs get along great...anyway...then...I was going through everything, had to deal with everything...had no energy for much else than getting through the surgery, then the radiation...focusing on staying positive...it was like, um...lost my train of thought...(smiles)...oh yeah...now our marriage is so QUIET...I thought to myself that Brad must be so bored, when will he be outta here...there's none of our usual energy...I couldn't do anything, participate in anything like we used to, all that stuff...so I was in the middle of this quiet...everyone else was out there, doing the normal things...and I thought, oh, this is way too middle-age for Brad, and what if this is the way it is...for good...I mean, I'll probably recover, lots of people do, but even if I recover, what's it going to be like...

R: So when you did recover, what did you...learn, how were things not like maybe what you were expecting? In the marriage, I mean?

Ellen: It was like I...took that quiet thing and brought it along with me...into the next phase...we related to each other differently, I think...it happened gradually...nothing intended...I liked our marriage before, it was great...but I guess it couldn't stay the same even if we'd wanted it to...before, it was like, there was a lot of fun, passion, excitement, up-and-down, run here, run there...but sometimes lots of arguing, turmoil, stress...I don't know about Brad, but I often felt, 'Is this gonna last? are we gonna make a go of this?'...our friends razzed us about it all the time, called us 'The Bickersons'...(chuckles)...so...afterwards...it just seemed like the atmosphere changed...it was so more peaceful...we seemed so more together...as if some step had been taken...but not consciously...but it was so different...

Brad: Different, yeah...(laughs)...but I knew...OK, things have changed...I knew...things would change, maybe change a lot...it was hard to imagine exactly how...I didn't have all that much time to think about it...maybe a good thing...but it was for sure a big-time learning experience...sink or swim kind of thing, see how you handle THIS, you guys!...lots of bein' in the dark...for me I mean...but looking back I think that was good...or...like they say that when you have something happen to you like cancer, you can have all the support around you you want but in the end you're alone with it...so, in a sense we were both alone with it, with Ellen having to make her peace with the surgery and the way things had changed for her, and me...just needing to be OK with it, not go nuts on her, stay strong...and I guess I learned how to do that...be strong when I was up against something I couldn't do anything about, really...couldn't begin to understand what she was going through...

Ellen: Yeah, I...he was so...dense about...the whole thing...we stayed apart a lot of the time...there was not much communication...I couldn't stand the sight of him sometimes...I read in a book that women often feel that way, something to do with the man representing...there's a fear, a really

powerful fear that he won't stay with you, he won't find you attractive anymore, so...you keep him away from you with anger so you antagonize him to the point where you...where your fears come true...

Brad: Yeah, there was plenty of pushing me away going on...not ACTUALLY, I mean not literally but...but I didn't go away, just kept buggin' her, tried to pretend things were goin' on just like normal...tried to make her laugh...

Ellen: I was oblivious...most of the time...I was in a world that people could visit, but they didn't live there with me...I was alone, I felt very, very alone, very isolated...but like Brad says he tried to pretend our life was going on just like before...that would infuriate me, but...at the same time it was...it was strangely...comforting...it was so BRAD...just keep chuggin' along, he's always been like that...he wanted me to believe that everything was the same between us, I guess...I was feeling that it couldn't be...I was almost resigned to it...maybe I talked myself into it, but I believed, in some way anyway, that...that he's...he's acting so normal, but what's really going on with him?...

R: Was there a time, a moment...some particular event or milestone...where you realized that...Brad is OK with this, with what has happened?

Ellen: I guess...um...well, I remember one afternoon, I was sitting in the big chair, it was a beautiful day, the cats were laying around, I had the afghan around me, Brad was out working on the side fence...he came in and...came in the living room...asked me how I was doing...asked me if I'd like to go to Restaurant A...our favourite restaurant...that night...said they were having some Mexican theme for the week or a couple of weeks...well...it, it was so like nothing had happened, like...I didn't immediately in my mind go to the cancer thing, to the not-feeling-well thing...I think it was the first time that didn't happen...I felt so calm, like some weight had come off me...I said 'OK, sure', but it occurred to me in that moment how hard it must have been for Brad, all those weeks...I'd never thought about that before...I was always so alone with my own stuff...and now for the first time I didn't feel like I was apart from him and he was just a big liar...really wanted to just get outta there...I felt this big...like a wave...of...I guess, what?, relief, happiness, love, who knows what else...I just said 'OK, sure', but...it was such a powerful feeling...I think that's when I REALLY started to recover, in the true sense of the word...since then it's been good between us...well, sometimes I still get nervous or irritated...I'm getting better, but it's still in the works...but ...well...

R: Brad, did you have any...similar experiences? When you knew it was gonna be OK?

Brad: Not really...I never knew what was goin' on! (laughs)...it seemed like she came around to speaking to me nicely again eventually...I do remember the retreat made a difference...but yeah, that night at Restaurant A though...it was very relaxed...Ellen didn't seem so...distant...she looked really good...don't ask me why, I don't remember any details...but...yeah, it was a good evening...and eventually she came around to...I guess accepting I was still there, OK, he's still here...through it all, I still thought she was my wife, in all that means...I wasn't planning on going anywhere...I mean it's normal to wish it hasn't happened, feel like you wanna be somewhere else...but you don't leave just because the dog has to have his leg amputated or the horse is going blind or somebody has a disease!...but she couldn't accept that...didn't think much of me, I guess!...so I waited it out, what else could I do?...so yeah, but when she really accepted that, it was a BIG relief...I was SO tired of...being the villain, I guess, feeling like I was doin' everything wrong...

Ellen: Well...I just...I was in another place...until that day...what can I say, I just had a realization...you need to focus on yourself, and then when you can you hope everyone will understand...

Brad: I do, now...

R: Mm-hmm...well...we're coming to the end of my questions...I just have two more...can you tell me, is there anything else about how the cancer experience has meant so much to you as a couple and how it has affected your marriage...now that you've had some distance from it, have gone through it and come out the other side...what is the ultimate meaning of the experience?

Brad: The whole couple thing...the marriage thing...it's such a struggle...you never think the other person's exactly right, you're always thinking of some way they should change, women more than

men I think!...but...that's kinda out of there for us...that all seems so pointless now...we coulda lost everything, the whole marriage...and we could easily have thrown it away, too...it's tough, it's one helluva tough ride, this cancer thing...but now...what was all that about?...what was so important that we'd have all these big fights...at this point we're not really going to change...stupid...stupid...so anyway...it's not like we don't fight now...we get into it sometime...but we don't have that antagonism like we used to...it's more calm...relaxed...

R: Mm-hmm...Ellen?

Ellen: Yes, it's definitely much calmer, much more relaxed...also I think...it's calmer and more relaxed because there's more of a level of respect going on...we're looking at two people who...went through hell, in their own individual ways, different hells, but still hell...and...you know, those two people did OK with it, learned from it, didn't let it destroy them...in fact, they're stronger now than they were before and hopefully the marriage is stronger too...I think it is...

Brad: Well, let's face it...we both feel 'Hey, why should we go through something like this and NOT survive?'(both laugh)...

R: Indeed...indeed...to wrap things up, can you tell me...in any way you want to answer this question, whatever feels right to you...why do you think you got cancer, why was it your marriage that it happened to?

Ellen: (long pause, sighs) I guess it was a test...I don't know any way to say it other than...there was no obvious reason, like heredity or bad health or bad diet...I really haven't thought much about it, but I guess you get tested in life by whatever and this was ours...who knows, who can say why some people get in a plane crash, why some people have Down's syndrome babies...I mean it doesn't make any real sense, you can't logic it out...like I said before, I don't think we really understand it, maybe it's better not to think about it too much...

R: Brad...any thoughts?

Brad: (shakes head)...you got me!...we just don't sit around agonizing about stuff...gotta leave that to all them philosophers and religious nuts...you know, like that Dipstick Chopra, tellin' everybody what's what...besides which, why is it so important?...it's really not gonna change things, so get on with your life, keep pluggin' away...there's not much else you can do...just be happy you passed the test and got outta there...

R: Mm-hmm...well...that's it for my questions...you've been terrific, and I really want to thank you...I so appreciate you giving me this time and sharing your thoughts and feelings with me...with such honesty and with such detail...we'll be meeting again soon, as I explained before, for the second interview, to corroborate my...to give you a chance to corroborate, validate my written findings from this interview.

END OF FIRST INTERVIEW

SECOND INTERVIEW

R: Thank you for coming to this second interview, I really appreciate your help. As I mentioned before, we'll be going over today what I have prepared from our first interview. I'll be giving you what I've prepared from our first interview, what we call the 'narrative account'. I'd like you to read it very carefully and make sure it's accurate, that it accurately represents the story of your cancer experience as a couple.

It's very important that the narrative account be accurate and that it represent as fully and completely as possible your experiences. Please do not hesitate to tell me if it is inaccurate in any way, or if something is missing, or if you are uncomfortable in any way with any of the information I have included.

I'd just like to review a few points from the consent form you completed before we started this process. Please remember, your participation is voluntary. You can withdraw at any time. I have used pseudonyms and removed other identifying information to protect your anonymity. And, if you have any questions, please do not hesitate to ask them.

Do you have any questions before we start the reading?

Brad: How long will it take? (laughs)

R: Well, I'd like you to read the narrative account carefully and thoroughly...I would estimate maybe a half hour to an hour?

Ellen: He's just kidding.

R: Ellen, do you have any questions?

Ellen: No, I don't think so.

R: OK then, here are the narratives. Please take your time.