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PSYCHOLOGICAL ADJUSTMENT OVER TIME TO THE SUCCESSFUL TREATMENT OF EARLY VERSUS LATE STAGE HODGKIN'S DISEASE IN YOUNG ADULT MEN

by

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VITA

The author, David Fitzgibbon Cella, is the son of Paul J. Cella and Barbara (Mason) Cella. He was born in Evergreen Park, Illinois, on March 29, 1955.

After elementary education at Queen of Martyrs grammar school, his secondary education was obtained at Brother Rice High School in Chicago, Illinois. He graduated in June, 1972, then entered Northwestern University as a Chick Evans Scholar and Illinois State Scholar in September, 1972. After three years of study at Northwestern University and one year of study abroad, he was awarded a Bachelor of Science diploma with high honors in psychology. The degree was conferred in June, 1976.

In September, 1977, he entered the graduate program in clinical psychology at Loyola University of Chicago. He was awarded a research assistantship in that year, and a USPH Fellowship in the following year. In January, 1981, he was awarded a Master of Arts degree in psychology. He pursued training in clinical psychology, including clinical appointments at The Children's Memorial Hospital (1979), Michael Reese Hospital (1980), Loyola University Counseling Center (1981), and The New York Hospital - Cornell University Medical Center (1982-1983). He was awarded a Schmitt Foundation Fellowship Award in September, 1982, for the purpose of dissertation research. He has published work in the area of psychometric assessment.

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INTRODUCTION

According to recent statistics, one of every five deaths in the U.S. is from cancer (American Cancer Society, 1982). Claiming over 1200 deaths per day, it ranks second to cardiovascular disease as the leading killer in our country. Because it can strike at any age, it is no surprise that cancer has been called "the most feared disease of the 20th century" (Holland, 1981). Indeed, many still equate the word cancer with death. This equation was reflected in the pre-1970 psychosocial oncology literature, which almost exclusively emphasized the dying process and coping in the terminally ill cancer patient (e.g., Kubler-Ross, 1969). One exception to this rule was the pioneering work of Arthur Sutherland on the psychological impact of cancer and its treatment on, for example, colon (Sutherland, Orbach, & Dyk, 1952) and breast cancer patients (Bard & Sutherland, 1955).

Attention to the problems of the surviving cancer patient has followed the progress of medical science in the treatment of cancer. In the early 1900's, surgery was the only treatment for cancer, so cure was possible only when the lesion was detected early and completely excised. The introduction of radiation therapies in the 1930's, and the addition of chemotherapy in the 1950's have dramatically improved the prognosis for many types of cancer. At present, a projected 38% (46% if one excludes death from other causes) of cancer patients diagnosed this year will still be alive in five years (American Cancer Society, 1982). Many of these will be off treatment, and may go on to live out their full life span. However, all of them hold a responsibility to their health which requires vigilance toward symptoms of relapse. Cancer is therefore better defined today as a chronic life-threatening illness, than as a fatal disease. Thus, today's "cured" cancer patient faces the same tasks as those suffering from any serious chronic illness. The National Cancer Institute has identified two general tasks which the cancer patient must confront: 1) coping with illness and its complications, such as pain or paralysis; and 2) coping with life as it is altered by illness (Blumberg, Flaherty, & Lewis, 1980). The present study is concerned with the second of these tasks. This task, relating to quality of life, has been further subdivided into four general categories: a) preserving a reasonable emotional balance; b) preserving a satisfactory self-image; c) preserving relationships with family and friends; and d) preparing for an uncertain future (Blumberg et al., 1980).

The advent of multimodal cancer treatment (including surgery, radiation, and chemotherapy) has ushered in a new era of cancer survival which makes the study of the above tasks possible. The paradox of this medical advancement lies in the legacy which it leaves behind: that most successfully treated cancer patients must face a new spectrum of problems that are related to the late (physiological) effects of treatment. "The normal physiology of virtually every organ or structure of the body can be impaired more or less by radiation therapy, chemotherapy, and their combinations" (D'Angio & Ross, 1981, p. 45). Consequently, whereas multimodal therapies have had dramatic positive effects on the survival rates of some cancers, they have also increased the risks of morbidity and mortality in the post-five-year period. These include risk of relapse, heightened risk of second malignancies (Li, 1977; Li, Cassady, & Jaffe, 1975), increased risk of carditis, pericarditis, and pneumonia (Desforges, Rutherford, & Piro, 1979; Jaffe, 1975), and permanent sterility (Sherins & DeVita, 1973; Sutcliffe, 1979). Because of this, the study of late, or delayed psychological effects of cancer and its treatment is a necessary one.

Globally, there are two conceptual models for understanding adaptation to survival from serious illness. The first views the direction of adaptive response as anticipatory vis-a-vis the prospect of death. This approach postulates a mechanism of anticipatory grief in the face of threatened loss, analogous to the experience of actual loss sustained in mourning proper. This approach borrows heavily from the phase-theory description of terminality by Kubler-Ross (1969). Thus, the patient, confronted with the diagnosis of cancer, is said to undergo a fixed sequence of bereavement responses, including denial, anger, bargaining, depression, and acceptance. Following from this scheme, the surviving cancer patient is said to be in a protracted state of anticipatory grief which gives rise to anxiety, depression, vulnerability, and death-related concerns.

The second conceptual model for survivor adaptation, and that embraced by this study, views the direction of adaptive response as residual vis-a-vis the past stressor of diagnosis and resulting treatment. In the medical psychology literature, the conceptualization of diagnosis (Katz, Weiner, Gallagher, & Hellman, 1970), the experience of illness itself (Lipowski, 1970), and the initiation of treatment

(Cohen & Lazarus, 1973; Janis, 1958) with life-threatening illnesses, are seen as stressors which are disruptive to homeostatic functioning. At present, the majority of studies of cancer survival lie in the area of adaptation to diagnosis and treatment itself. The next clinical event associated with psychological disruption is disease recurrence, frequently responded to with elevated depression and anxiety, because the patient is confronted with the failure of treatment (Silberfarb, 1982; Silberfarb, Maurer, & Crouthamel, 1980). Subsequent risk for increase in anxiety and depression are also expected at cessation of a successful course of treatment, when the patient confronts the twin demands of separation from the therapy milieu and re-entry into personal lifestyle (Holland, Rowland, Lebovits, & Rusalem, 1979; Sutcliffe, 1979). There is also widespread confirmation that trait classification of global adaptational capability (Koocher & O'Malley, 1981), coping adequacy (Penman, 1979), ego strength (Worden & Sobel, 1978), and level of distress (Sobel & Worden, 1979), as measured on various state variables, differentiate poor from good adjustment during these periods.

The next logical step in psychosocial adaptation research is the investigation of long-term sequelae. In a recent comprehensive review article, the understanding of the long-term impact of cancer is given as one of the key questions which remains unanswered in psychosocial oncology (Freidenbergs, Gordon, Hibbard, Levine, Wolf, & Diller, 1981-82). Information in this area is cited as essential to "facilitate the development of a systematic psychosocial intervention program for the cancer patient" (p. 315).

This study attempted to evaluate psychological functioning in a successfully treated sample which is not currently plagued by treatment side-effects or by reactions to recurrence. All patients have been disease and treatment free for a minimum of six months. This enabled an unprecedented retrospective study of psychological adjustment in young adult male Hodgkin's disease patients who have been successfully treated. Besides the general cancer variable, the independent variables of interest were severity of disease stage (early vs. late) and time off treatment (recent vs. distant). Dependent measures assessed psychosexual dysfunction, psychiatric symptomatology, mood states, death anxiety, self-esteem, coping style (thinking), psychosocial problems in interview, and readiness for intimacy (intimacy motivation).

Adaptation is the central concept in this study. The term "adaptation" is preferred over "coping" (adaptation under difficult conditions), "mastery" (behavior in which frustration is surmounted), and "defense" (response to danger). As explained by White (1976) and Sutherland (1956), adaptation (to cancer) would focus on the chronic process of adjustment (to cancer) and its subtle intrustions upon homeostatic functioning. This is the outlook preferred also by Silberfarb (1982). Thus, the young adult cancer patient is constantly confronted with the realization that he is different from those around him. He must make adjustments to account for the unique stressors of untimely disease, debilitating treatment, and chronic uncertainty. This study attempts to measure these adjustments by comparing Hodgkin's disease patients to an age-matched healthy comparison group, and to themselves across the variables of disease stage severity and time off treatment. Dependent measures were chosen and hypotheses made according to the available cancer survivor literature.

The choice of young adult men as the target population for this study came in part from consideration of relevant developmental tasks in this age group. For example, Erikson (1950) considers the central task of this group to be the development of a capacity for intimacy, or a sense of mutuality with a loved partner, with whom the individual regulates work, procreation, and recreation. Young adulthood is a time of beginnings in personal, social, and occupational spheres. The impact of a major disease at this time in life is usually both a surprise and a source of resentment. In the case of all participants chosen for this study, it was the first time they experienced any real threat to their lives.

To summarize, this study attempts to identify problems in adaptation to cancer which young men face in the post-treatment period. Because of its view on adaptation as described by White (1976), the investigation concerns itself as much with day-to-day adaptational difficulties as it does with more overt problems which may surface. Each individual is seen as striving toward suitable compromise rather than mastery in the face of adversity, and so the study will at times seek to determine unique patterns of adjustment rather than necessarily a picture of psychiatric morbidity or exaggerated stress-response syndromes.

It was decided on methodological grounds to limit the investigation to one form of cancer (Hodgkin's disease) and one sex (male).

Men were chosen over women on the supposition that they would represent a more homogeneous group with regard to occupational goals, and because literature to be reviewed later has identified the young male patient as at higher risk for post-treatment interpersonal difficulty (Leiber, Plumb, Gerstenzang, & Holland, 1976). Hodgkin's disease was chosen for three reasons: 1) its status as a "good prognosis" cancer, with five-year survival rates ranging from 70% (late stage) to 90% (early stage) (American Cancer Society, 1978); 2) peak incidence in young adults; and 3) the debilitating quality of the combined modality treatment for Hodgkin's disease.

REVIEW OF THE RELATED LITERATURE

This chapter is divided into two main sections. The first section describes Hodgkin's disease in terms of its pathology, staging, and treatment. Specific attention will be given to treatment procedures at Memorial Hospital in New York City since the current sample comes from there. The second main section reviews the available literature on the late psychological and psychosexual effects of successful treatment of Hodgkin's disease in particular and cancer in general. At the end of the second section are presented the hypotheses of the study.

Hodgkin's Disease and Its Treatment

Hodgkin's Disease: Description and Epidemiology

Definition of the disease. Hodgkin's disease is a form of lymphatic cancer which accounts for approximately 40% of all malignant lymphomas. Lymphomas in turn account for around 5% of all cancers (American Cancer Society, 1982). It can strike at any age, but incidence generally follows a bimodal curve, peaking between 15 and 34, and then again after age 50. In this 15-34 age group, 66% of all lymphomas are Hodgkin's lymphomas (Schottenfeld, 1976).

Hodgkin's disease usually presents as a painless rubbery swelling, usually in the supraclavicular or cervical node areas. Axillary and mediastinal node masses are also common. It may or may not be associated with symptoms such as fever, night sweats, or weight loss (Ultmann & Stein, 1979). Pruritis and alcohol sensitivity are other possible symptoms which are much less common.

Hodgkin's disease is diagnosed histologically, where the essential feature is the presence of the multinucleated "Reed-Sternberg" giant cell. Thus, a patient must receive a biopsy before diagnosis can be made definitively. Once diagnosis is established, the disease must be subclassified and staged. Subclassification is according to the Rye (Rye, New York Conference, 1966) histologic classification system (Lukes, Craver, Hall, Rappaport, & Rubin, 1966), and includes four subtypes. The first three, lymphocyte predominant, mixed cellularity, and lymphocyte depleted, are on a continuum of the same basic "diffuse" pattern. The lymphocyte predominant subtype has an abundance of normal lymphocytes, sparsely distributed granulocytes, and only occasional malignant Reed-Sternberg cells. The lymphocyte depleted subtype involves most of the normal lymphocytes replaced by fibrosis and usually an abundance of Reed-Sternberg cells. The mixed cellularity subtype lies between these two extremes, with moderate numbers of lymphocytes and granulocytes as well as readily-identifiable-but-not-abundant Reed-Sternberg cells. The fourth histologic subclassification is the nodular sclerosing subtype, a qualitatively different subtype which shows a nodular patterning of cells and "lacunar" Reed-Sternberg cells (i.e., retraction of cell cytoplasm, leaving the Reed-Sternberg cells in an apparent space, or "lacuna"). This nodular sclerosing subtype is the most common (60%), especially in the young adult patient group (Schottenfeld, 1976). Compared to the lymphocyte depleted and mixed cellularity subtypes, it is also the most benign in terms of its progression in the absence of treatment (Desforges, Rutherford, & Piro, 1979).

Staging of Hodgkin's disease. While histologic subclassification is important in helping to determine appropriate treatment and prognosis, staging is critical. The stage of Hodgkin's disease is the single most important prognostic indicator and is usually the best guide to appropriate treatment (Ultmann & Stein, 1979). The commonly accepted staging criteria are those which were established at a 1971 oncology conference in Ann Arbor, Michigan (Carbone, Kaplan, & Musshoff, 1971). These Ann Arbor criteria delineate four distinct stages: Stage I (involvement of a single lymph node region or of a single extralymphatic organ or site); Stage II (involvement limited to one side of the diaphragm, either of two or more lymph node regions or localized involvement of an extralymphatic site and at least one lymph node region); Stage III (involvement of lymph node regions on both sides of the diaphragm, which may include localized involvement of an extralymphatic site or spleen); and Stage IV (diffuse or disseminated involvement of one or more extralymphatic organ or any liver involvement, with or without associated lymph node involvement) (from Desforges et al., 1979). Each patient is then further classified as either "A" (asymptomatic) or "B" (symptomatic). The three cardinal symptoms, at least one of which is necessary for "B" status, are: 1) unexplained weight loss of at least 10% of total body weight in the past six months; 2) unexplained fever, with temperatures above 38° centigrade; and 3) night sweats. The most common stages diagnosed are IA, IIA, IIIA, IIIB, and IVB. IB is especially rare, and IIB and IVA somewhat rare (Schottenfeld, 1976). Some diagnosticians also like to add the subscript "s" to denote splenic involvement (common in later stages), and the subscript "e" to denote the involvement of an extralymphatic site primarily or by direct extension (e.g., mediastinal mass which has extended to involve a lung) (Ultmann & Stein, 1979). This study did not concern itself with the "s" or "e" subscripts because they are not deemed critical in the staging process at Memorial Hospital. That is, decisions about appropriate treatment at Memorial are generally made by determination of stage number and the presence or absence of B symptoms.

Treatment of Hodgkin's Disease

Before discussing the four specific patient protocols relevant to this study, a general review of the development of Hodgkin's disease treatment over the past 50 years will be furnished as background information.

Background: Development of the treatment of Hodgkin's disease.

The three general treatment modalities for Hodgkin's disease in particular and cancer in general have been mentioned. They are surgery, radiation, and chemotherapy. Prior to 1950, radical surgery followed by diffuse radiation was the principal treatment (Kaplan, 1980). The five-year survival rate during the 1940-1949 decade was 25% (Schottenfeld, 1976). Over the past 30 years, the development of megavoltage radiotherapy apparati, with "mantle" and "inverted Y" fields constructed to protect the body outside of the lymph node areas has permitted much more aggressive (high voltage) radiation treatment. This helped bring the five-year survival rate to around 42% by 1960. Combined with the disadvantages of cosmetic disfigurement of radical surgical techniques, this improvement in radiation technology has led to the wane of surgery as a common primary treatment for any but the most severe cases of Hodgkin's lymphomas (Kaplan, 1980). Surgery is still indicated for some cases of extralymphatic organ involvement, however (e.g., splenectomy).

The third modality, chemotherapy, has recently introduced even more dramatic survival rates, to the point where some are willing to use the term "cure" for Hodgkin's disease (e.g., Desforges et al., 1979). After World War II experimentation with mustard gases, it was discovered that nitrogen mustard and its derivatives were effective against leukemias and lymphomas (Kaplan, 1980). This drug was first shown to be effective against Hodgkin's disease by Rhoads (1948), in a clinical trial at Memorial Hospital. In the 20 year period following World War II, numerous other tumoricidal agents have been introduced and used in various combinations (see Krakoff, 1981).

It is an accepted fact in cancer medicine that chemotherapy for Hodgkin's disease using more than one agent (called "combination chemotherapy") is more effective than chemotherapy with single agents, when considering response rates (how many people of those treated enter remission) and length of remission period (Carter & Goldsmith, 1976; DeVita, Serpick, & Carbone, 1970; Krakoff, 1981; Wittes & Lacher, 1976). The first successful combination chemotherapy regimen for Hodgkin's disease, tried by Lacher and Durant (1965), included vinblastine and chlorambucil. They achieved a complete response rate (percent of patients who show no evidence of disease after treatment) of 62% in early stage patients. But the most dramatic advancements during this period took place within the National Cancer Institute of the National Institutes of Health (NCI). The first NCI combination for Hodgkin's disease included cyclophosphamide, vincristine, methotrexate, and prednisone given in conjunction with radiotherapy (Moxley, DeVita, Bruce, & Frei, 1967).

A second and more successful combination chemotherapy devised at NCI by DeVita and colleagues (Canellos, Schein, Chabner, Bagley, & Young, 1973; DeVita & Serpick, 1967; DeVita, Serpick, & Carbone, 1970) is referred to as the "MOPP" regimen. MOPP is the acronym for Mustargen^R(nitrogen mustard), Oncovin^R(vincristine), procarbazine, and prednisone. Initial reports of this regimen on 43 patients in an uncontrolled study claimed 81% complete remission and 14% partial remission, for an overall response rate of 95%. Seven year disease-free survival was reported in 15 (43%) of the 35 complete remission patients (DeVita et al., 1973).

Since 1973, research in the treatment of Hodgkin's disease has centered around this MOPP regimen, usually comparing it to radiation therapy alone or to other combinations of chemotherapeutic agents. So far, some combinations of drugs have been found to be as effective as MOPP, but none has been proven definitively better (Desforges et al., 1979).

In summary, research and advancements over the past 50 years in the science and technology of radiation therapy, and in the use of combined tumoricidal chemical agents has transformed Hodgkin's disease from an almost invariably fatal illness to one that is quite frequently cured. Recently the American Cancer Society (1978) has reported 90% five-year survival in early stage disease.

Research on the treatment of Hodgkin's disease at Memorial Sloan-

Kettering Cancer Center is dedicated to further improvement of response and survival rates. This research consists of randomized clinical trials of various combinations of chemotherapy and radiation treatment for different stages of the disease. The next subsection will describe the four clinical trial treatment protocols which are relevant to this study.

Memorial Hospital treatment protocols. Memorial Hospital for Cancer and Allied Diseases is the treatment unit of the Memorial Sloan-Kettering Cancer Center. Located on the East side of Manhattan, it is a major tertiary referral hospital for patients with cancer from all parts of the country. The hospital provides care for approximately 16,000 inpatients per year and records nearly 140,000 outpatient visits per year (1980 hospital statistics). Except for initial biopsy and staging procedures, as well as disease or treatment complications, all of the treatment for Hodgkin's disease is done on an outpatient basis.

After a patient with suspected lymphoma is given a biopsy and Hodgkin's disease is histologically diagnosed, staging is the next step. It is the severity of disease stage which determines the placement into treatment protocol. Two of the four relevant treatment protocols are for early stage patients and two for late stage patients. They will be discussed in that order.

Table 1 presents a summary of the four Memorial Hospital Hodgkin's disease treatment protocols. The first early stage protocol was in effect from 1975 to 1981, while the second has been in operation since then (1981-present). The first protocol (M.H. #75-103) called for six

Table 1

Basic Overview of Four Memorial Hospital

Treatment Protocols

Protocol Number	Years in Use	Disease Stages Applicable	Treatment Length	Estimated Radiation	Chemotherapy Agents
75-103	1975-1981	Early: IA, IB, IIA, IIB, IIIA	7 months	3500 rads (@ 5000 rads for IIIA)	MOPP
81-103	1981-present	Early: IA, IIA, IIIA	5 months	3500 rads	MOPP or TBV
75-104	1975-1979	Late: IIB (unfav.) IIIA (unfav.) IIIB, IVA, IVB	24 months	@ 5000 rads	MOPP/ABDV
79-17	1979-present	Late: IIB, IIIB, IVA, IVB	11 months	@ 3500 rads (more as needed)	MOPP/ABDV or MOPP/ABV/CAD

28-day cycles of the MOPP chemotherapy regimen with one month of involved field radiation "sandwiched" in between the six cycles. Each cycle consisted of 14 days on treatment and 14 days off treatment. Dosages were as follows: Day 1 and 8, nitrogen mustard 6 mg/m^2 i.v. (max. 10 mg), and vincristine 1.4 mg/m^2 i.v. (max. 2 mg); Days 1-14, procarbazine 100 mg/m^2 p.o. (max. 150 mg), and prednisone 40 mg/m^2 p.o. (cycles 1 and 4 only). When patients could not tolerate the nausea and vomiting from the nitrogen mustard, cyclophosphamide 650 mg/m^2 i.v. (i.e., "COPP"), or Thio-tepa 15-18 mg/m^2 i.v. (i.e., "TOPP"), was substituted. Also, other deviations from this protocol were occasionally made for individual patients due to drug reactivity, drug toxicity, poor early response, or side-effect intolerance. The same is true of all four protocols.

The seven month treatment protocol just discussed was proposed because of high relapse rates reported for early stage patients who were successfully treated with radiation alone (40-60%). It was conceptualized as an attempt to heighten survival rates in "favorable" prognosis patients who would previously have received the more standard radiation-only treatment. Memorial Hospital investigators included stages IA, IB, IIA, IIB, and IIIA in this "favorable" group. Experience with patients on this protocol showed that IIB patients had significantly more non-complete responders, and so this subgroup was switched to the late stage group for the more recent protocols.

The second early stage protocol (#81-103) began in 1981 and has been used with stages IA, IIA, and IIIA patients. Prior experience with early stage patients at Memorial Hospital revealed clear gains in induction and duration of remission with the combined modality approach over the radiation-only approach (Koziner, Braun, Garrett, Nisce, Young, Lee, & Clarkson, 1978). However, concern over the additive risks to endocrine and gonadal function and the increase in future second malignancies from highly cytotoxic agents in combination with radiation has led to efforts at finding a chemotherapy regimen of equal (if not better) efficacy to MOPP, which might have lowered long term health risks. Thus, the second early stage protocol randomized patients into one of two groups: MOPP plus segmental radiotherapy, or "TBV" plus segmental radiotherapy. TBV (Thio-tepa, vinblastine, and bleomycin) is hoped to be connected with less post-treatment oncogenicity and fewer post-treatment gonadal disturbances than MOPP. Results are not yet available on this.

The treatment schedule on protocol #81-103 was as follows: four 28-day cycles of MOPP (or TBV) with a one-month period of radiation therapy "sandwiched" in between. MOPP dosages are the same as in protocol #75-103, but there are now two fewer chemotherapy cycles (six lowered to four). Total treatment time is therefore cut from seven to five months. The TBV dosages are: Days 1 and 15, Thio-tepa 35 mg/m^2 i.v., vinblastine 6 mg/m^2 i.v. (max. 10 mg); and days 4-12, 18-26, bleomycin 2 mg/day subcutaneously.

The two late stage protocols are M.H. #'s 75-104 (1975-1979) and 79-17 (1979-present). These involve more aggressive treatments which attempt to produce complete remission rates superior to the MOPP plus radiotherapy regimen typically used. Protocol #75-104 used eight drugs (MOPP/ABDV) plus radiation over a course of 24 months. This approach alternated (by monthly cycle) the use of MOPP with that of ABDV (adriamycin, bleomycin, DTIC, and vinblastine), a combination found to be as effective as MOPP by Bonadonna, Zucali, and Monfardini (1975). In the first four months the patient received alternate cycles of MOPP and ABDV. The fifth month was for radiation treatment. The sixth through ninth months proceeded identically to months one through four. Months 11, 13, 15, 17, 19, 21, and 23 were alternating MOPP, then ABDV cycles. The even numbered months were reserved for immunotherapy in half the group and no treatment in the other half. MOPP dosages were essentially the same as in protocols described earlier. ABDV cycle schedule of drugs and dosages were: Days 1 and 15, adriamycin, 25 mg/m^2 i.v., vinblastine 6 mg/m^2 i.v. (max. 10 mg), and DTIC 250 mg/m^2 i.v.; and Days 4-12, 18-26, bleomycin 2 mg/day subcutaneously. From 1975 until 1979, this was the standard treatment for Hodgkin's disease patients of stage IIIB, IVA, and IVB, as well as certain IIB and IIIA patients with "unfavorable" prognosis. As with other protocols, variations in these drug and dosage schedules occurred in individual cases where clinical considerations of toxicity, drug intolerance, or disease course overrode research interests.

The fourth and final protocol relevant to this study (#79-17) has been used with stages IIB, IIIB, IVA, and IVB at Memorial Hospital since 1979. It compares the earlier-mentioned eight-drug schedule (#75-104) to a still newer 10-drug regimen. Total treatment time is shortened (by lessening the number of cycles given) from 24 months to 11 months in the late stage group. The drug schedule and dosage of MOPP/ABDV cycles is the same as that outlined in the previous protocol.

The 10-drug regimen, MOPP/ABV/CAD (MOPP + ABV + CCNU, alkeran, and DVA), is administered in the following order (28 day cycles): CAD-MOPP-ABV-CAD-MOPP-ABV-radiation-two weeks rest-CAD-MOP (no prednisone)-ABV. Cycle schedule of drugs and dosages are nearly identical to other protocols for MOPP, ABDV, and ABV. The CAD cycle schedule is as follows: Day 1, CCNU 100 mg/m^2 p.o.; Days 1 and 8, DVA 3 mg/m^2 i.v.; Days 1-4, alkeran 6 mg/m^2 p.o. Note that the patient is afforded three to four weeks rest in each CAD cycle.

It is hoped that this fourth protocol, with the addition of new agents, will eradicate residual tumor cells resistant to the first two combinations (MOPP/ABDV). Less attention is paid to possible late toxicologic effects of treatment (e.g., sterility, leukemia, secondary non-Hodgkin's lymphoma, chronic carditis) in these late stage treatment protocols than in those for early stage disease.

The continual advent of new cytotoxic agents, and their addition to existing chemotherapy combinations, represent an increase in physiological side effects and future health risks to the patients. That is, not only are treatments becoming more successful with time, but they are also becoming more toxic to the patients. Attention will now turn to a brief review of late physiological effects which have been associated with these treatments. The discussion will be divided into radiation effects and chemotherapy effects. Because late stage patients are generally treated with slightly more radiation and always receive much more chemotherapy (in dosage and duration), they are obviously at higher risk for all that is described in the next two subsections. The fact of greater treatment severity in late stage patients was one reason for conceptualizing the study hypotheses in terms of early versus late stage differences. That is, not only are late stage patients "sicker," and therefore closer to death, than early stage patients, they also receive a more aggressive treatment with more debilitating and potentially lethal aftereffects. This will be discussed later, but is mentioned now for the reader's consideration while reviewing delayed treatment effects and risks incurred by all patients.

Radiation treatment: Physiologic effects and potential risks. Radiation treatment (RT) for Hodgkin's disease is a focused attempt to limit lethal doses of radiation to the area of the lymph nodes and organs involved in the disease. The refined techniques of "mantle" and "inverted Y" field irradiation have reduced many of the complications of RT for lymphoma. However, the proximity of the lymph nodes to so many vital organs means that risk, while reduced, is by no means eliminated. One can consider the risks of RT in Hodgkin's disease starting from the most anterior nodes (neck and armpits), moving down to the most posterior ones (gonads and groin). Stage I and II patients by definition receive RT to one or the other side of the diaphragm, while Stage III and IV patients get RT to both sides.

Beginning with the most anterior nodes and working downward, long-term pituitary and thyroid abnormalities, including alterations in serum thyrotropin and reports of thyroid disease, have been associated with neck irradiation (Schimpff, Diggs, Wiswell, Salvatore, & Weirnik, 1980). Radiation induced bone sarcoma (Smith, O'Connell, Huvos, & Woodward, 1980), malignant peripheral nerve sheath tumors

(Foley, Woodruff, Ellis, & Posner, 1980), and radiation myelopathies (Word, Kolokhe, Aron, & Elson, 1980) have also been reported. The risk of secondary leukemia is also slightly elevated (Desforges et al., 1979). Increased susceptibility to later infections, especially when paired with splenectomy and/or chemotherapy, is another known risk of radiation (Donaldson, Glatstein, & Vosti, 1978). Post-treatment cardiac and pulmonary complications, such as carditis, pericarditis, pericardial effusions, chronic pericardial disease, pneumonitis, and transient pulmonary dysfunction have frequently been identified (e.g., Cole, Pollack, Sutton, Slawson, Singleton, & Weirnik, 1981; Gross, 1977). In certain cases, the addition of chemotherapy to radiation has an additive effect on radiation complications. For example, prednisone after radiation may draw out a latent pneumonitis or pericarditis when discontinued abruptly, and bleomycin seems to combine with radiation in a way which is hazardous to lung tissue (Desforges et al., 1979).

A final radiation complication relates to reproductive function. In men, aspermia results in 70-100% of patients irradiated below the diaphragm, despite efforts to shield the gonads (Speiser, Rubin, & Casarett, 1973). Reports of return of spermatogenesis in these patients range from 0% to 80% over a three-year post-treatment period.

Chemotherapy: Physiologic effects and potential risks. The use of combination chemotherapy plus radiation therapy in early stage Hodgkin's disease is controversial, because evidence for its superiority over radiation therapy alone is mixed, and because it is associated with so many more complications. The risk of secondary acute leukemia and non-Hodgkin's lymphoma from combined modality treatment has been recognized by many investigators (Arsenaau, Canellos, Johnson, & DeVita, 1977; Cadman, Capizzi, & Bertino, 1977; D'Angio, Clatworthy, Evans, Newton, & Tefft, 1978). Pedersen-Bjergaard and Larsen (1982) staged and treated 391 Hodgkin's disease patients from 1970-1981. Of the 312 treated with combined chemotherapy and radiation or chemotherapy alone, 17 developed preleukemia or an acute myeloproliferative syndrome with bone marrow abnormalities. A Kaplan-Meier estimate of the cumulative probability of leukemic complications was 3.9 ± 1.3% five years after treatment began, and 9.9 ± 2.9% at nine years. Of the 79 patients treated with radiation alone none had any leukemic complications ($\underline{p} < .01$). The risk of non-Hodgkin's lymphoma at 10 years off treatment has been reported at 4.4% (Krikorian, Burke, & Rosenberg, 1979).

Combination chemotherapy has also been associated with lowered immunity against common infections (e.g., Steele & Han, 1978), and frequent susceptibility to herpes zoster (Cunningham, Mauch, Rosenthal, & Canellos, 1982). Chemotherapy for Hodgkin's disease is connected to almost certain sterility in males. The best current estimate is between 80-90% sterility three years after treatment (Chapman, Sutcliffe, Rees, Edwards, & Malpas, 1979; Schilsky, Lewis, Sherins, & Young, 1980; Sherins & DeVita, 1973). A retrospective study of 52 young adult men over three years off treatment yielded an estimate of over 90% sterility in men who had been treated with six cycles of MOPP chemotherapy (Cunningham et al., 1982). This 90% figure has been confirmed here at Memorial Hospital in a prospective study of 60 men treated for Hodgkin's disease over the past four years (Redman, 1983).

This is a tremendously significant issue for successfully treated young men who are faced with return to "normal life," most often realizing that they will very likely never father children in a "normal" way (Sutcliffe, 1979). What is more, a recent prospective study by Chapman, Sutcliffe, and Malpas (1981) found 16 (43%) of 37 men to be functionally subfertile before initiation of treatment. A more recent study (Vigersky, Chapman, Berenberg, & Glass, 1982) has confirmed this figure, and found it to be significantly greater than that in other malignancies. This clearly suggests compromised fertility as a result of the disease itself, implying that efforts to bank sperm prior to treatment may not be a viable alternative for these patients. In the 1981 study, 100% (14 of 14) of the patients tested became persistently azoospermic after only two cycles of chemotherapy with MOPP.

Taken drug-by-drug, in single administration the alkyllating agents of chemotherapy (nitrogen mustard, cyclophosphamide, and Thio-tepa) have been associated with bone marrow toxicity, nausea and vomiting (which can linger on after treatment is over via conditioning), myelosuppression, alopecia, and hemorrhagic cystitis (Wittes & Lacher, 1976). The vinca alkaloids (vinblastine, vincristine) have been linked to RNA synthesis inhibition, myelosuppression, and neurotoxicity, especially peripheral neuropathies, which can last for life (Wittes & Lacher, 1976). Procarbazine is also linked to nausea and vomiting which can persist, reduced white blood count from myelosuppression, and thrombocytopenia. Prednisone, a glucocorticoid agent, is associated with the usual spectrum of steroid-related side effects (Cushingoid symptoms), which are usually reversible.

In summary of this section, three points were highlighted. Recent years have brought new advances and success to the treatment of Hodgkin's disease. Successful treatment generally includes both radiation and chemotherapy. The exact combination and intensity of treatments are dependent upon the stage of the disease at diagnosis. Although treatment has become quite successful, it does exert a more general impact on the body which results in unpleasant side effects and potential long-term health problems. There is also some question about the possible psychological and psychosocial impact of this newly achieved successful treatment for Hodgkin's disease. The next main section will review the literature relevant to these possible psychological concerns.

Psychological Adjustment to Cancer and Its Treatment: Literature Review

Background Literature

As emphasized in Chapter 1, adaptation to (rather than coping with, mastering, or defending against) cancer is the central concept of this study. The literature review will focus on the empirical research which has been done on cancer survivors off treatment. While the crisis model, as introduced by Lindemann (1944) is not central to the study, it is intermixed with the idea of adaptation in that all individuals with cancer seem to cope through a gradual integration of this life-threatening crisis (Holland, 1982b; Weisman, 1976).

Therefore, a brief overview of research in coping with cancer survival influenced by the crisis theory model will also be presented.

As early as the 1950's, Sutherland and colleagues had clinically identified a heightened incidence of post-treatment anxiety and depression in successfully treated cancer patients (Bard & Sutherland, 1955; Sutherland, 1956). Their work was primarily with breast and colon cancer patients. Systematic investigation of these observations pinpointed examples of anxiety about recurrence (including hypochondriacal concerns), development of dependent personality features, and increases in obsessive-compulsive and paranoid reactions, as well as general family strife (Sutherland, 1956). In his discussion of these findings, Sutherland postulates that a cancer patient's pattern of adaptation, defined as "a system of beliefs and behavior designed in order to bring the individual's physical and emotional needs in harmony with the demands of the environment," is threatened by cancer. With the homeostasis of the organism threatened, the patient is then subjected to loss of self-esteem and anxiety secondary to the subjective isolation of being a cancer patient. Bard and Sutherland (1955) followed 20 breast cancer patients prospectively, from the pre-operative period to recovery. From their findings, they formulated three phases of adaptation to mastectomy (and cancer treatment in general): 1) anticipatory phase, where the patient speculates with fear and uncertainty about the damage to self and disruption of previous levels of adaptation; 2) operative phase, where the actual injury (crisis) occurs; and 3) reparative phase, where the patient attempts to reestablish his or her previous level of adaptation by a variety of techniques. This study is intended to focus upon this third, reparative phase of adaptation to cancer.

Based upon her review of the psychosocial oncology literature, Holland (1981) has outlined eight psychiatric syndromes relevant to cancer patients. Six of them hold some relevance to patients off all treatment and free of disease; that is, patients in Bard and Sutherland's (1955) reparative phase. They are: 1) acute stress reactions such as reactive anxiety and depression, including prolonged or delayed reactions to survival and cure; 2) major psychiatric disorders (DSM III Axis I pathology) with onset during or after treatment; 3) anxiety disorders such as conditioned nausea, conditioned vomiting, phobias, or panic reactions; 4) somatoform disorders such as hypochondriasis; 5) psychosexual disorders resulting from the illness or treatment; and 6) personality disorders which can complicate and interfere with post-treatment adjustment. "Quality of life" after treatment, according to Holland (1981, 1982a, 1982b) depends to a great extent upon the patient's prior level of emotional adjustment and the presence of emotionally supportive persons in the environment.

The concepts of crisis and stress management are relevant to this study inasmuch as adaptation to cancer survival entails some measure of protracted distress. Ever since Hans Selye first formulated the concept of "stress" as a syndrome with physiologic correlates and potential vulnerabilities to the distressed organism (Selye, 1936), researchers have been intrigued by the relationship between stress and illness onset (Lazarus, 1974, 1976; Selye, 1975; Tache, Selye, & Day, 1979). A kind of reversed approach to this involves the conceptualization of illness (and treatment) as a stressor in itself which can lead to further organism distress (Caplan, 1981; Horowitz, 1976). Lindemann (1944) pioneered this idea in his study of personality changes due to distress in the bereaved friends and relatives of the Coconut Grove fire victims. Application of this idea to cancer patients by Horowitz and colleagues (Horowitz, 1976; Horowitz, Wilner, & Alvarez, 1979) views cancer adaptation as a process parallel to stress-response syndromes in general. In a study of cancer patients at the point of diagnosis and during treatment, Horowitz, Wilner, and Alvarez (1979) found cancer patients to use alternating combinations of intrusive and avoidant thinking styles. They measured this with their Impact of Events Scale, a 15-item, self-report inventory. The pattern of coping which they detected in their cancer sample was similar to, though less dramatic than, that found in their stress-response clinic outpatients.

Caplan (1981) has presented a model for understanding stress-response behavior such as that seen in cancer patients. His focal construct is "mastery," defined as behavior which both reduces the physiologic and psychologic manifestations of emotional arousal during and shortly after the stressful event; and mobilizes the individual's internal and external resources, thereby developing new capabilities which lead to the person's changing of the environment or his/her relation to the environment, so that threat is reduced or so that alternate sources of satisfaction replace what is lost. In the case of cancer, one's health and certainty about the future are the lost entities.

Caplan also explains four interdigitating phases of mastery in the face of stress: The first is escape or avoidant behavior which enables the individual to tolerate the intensity of the stress; the second involves acquisition behavior in which the individual attempts to change unfortunate circumstances and their aftermath. One can easily parallel these first two phases to the general periods of diagnosis and treatment of the illness itself. The third and fourth phases are more relevant to this study in that they seem to describe the post-treatment adaptational challenge. Phase three entails intrapsychic behavior which defends against intrapsychic emotional arousal. Denial or avoidance of anxiety, hostility, depression, and grief are the most common mechanisms. The fourth and final phase, according to Caplan, involves synthetic intrapsychic behavior which integrates the stressful experience (diagnosis and treatment) and its sequelae (chronic uncertainties) by internal readjustment.

Following the general idea of crisis theory that individuals resolve crises within six to eight weeks (see Talpin, 1971), Lewis, Gottesman, and Guttstein (1979) studied 35 cancer patients over a 28 week period after surgery. They found this notion of rapid crisis resolution not applicable to their cancer sample. Measuring anxiety, helplessness, depression, self-esteem, and general level of crisis, five variables considered by crisis theorists to be basic indicators of crisis, they found that scores were still rising eight weeks after surgery, regardless of its outcome. Follow-up at 28 weeks did find scores beginning to decline, however. The results suggested either the inapplicability of a straightforward crisis model for cancer patients or the need for modification of the time needed for crisis resolution in a cancer population. In a follow-up to this study, Gottesman and Lewis (1982) compared 31 female cancer surgery patients to 15 medical surgery patients and 15 healthy women. Both cancer and surgery groups scored higher than healthy women on the Halpern Crisis Scale. However, the cancer sample scored as significantly more helpless than the surgery patients. Discriminant function analysis resulted in 73-82% accuracy of placement into the three groups, suggesting that cancer surgery and non-specific medical surgery may represent separate types of crisis. The increase in helplessness in the cancer sample was evidence for a different, perhaps more depressive, reaction in the cancer patient sample. This provides indirect evidence for cancer adaptation as a process which is distinct from and more prolonged than adaptation to general medical illness and surgery. Incidentally, this study also found that the average time needed by the cancer surgery sample for crisis resolution was 15 weeks; again longer than the expected six to eight weeks.

Studies on the Problems of Return to Premorbid Lifestyle in Successfully Treated Cancer Patients

Chronologically, the first event associated with adaptation to cancer survival is the return to premorbid lifestyle immediately after treatment ends. The process of reentry of the treated cancer patient into society's mainstream and the return to his or her premorbid lifestyle has been referred to as the "Lazarus Syndrome." This analogy to the biblical character who returned from the dead is not so far-fetched when one considers the many accounts from patients and clinicians of patients' being treated by significant others as either dead or dying during the treatment period (e.g., Sveinson, 1977; Zubrod, 1975). The sense of being somehow different from others and permanently changed by the cancer experience has been described by a cured Hodgkin's disease patient as follows: "(the diagnosis of cancer) marks the start of a new way of life. Up to this point, the man/woman has enjoyed normal health with no major problems. But now, with a serious illness, he puts everything else aside. He starts a new life" (Sveinson, 1977, p. 83). Thus, the termination of treatment and reentry into "normal" life can be seen as a stressor in itself, characterized by a letdown of the struggle against death and the challenge of return to normalcy (Holland et al., 1979; Sutcliffe, 1979; Zubrod, 1975).

Clinical case reports of post-treatment disruption of basic psychosocial areas of socialization, financial security, vocational development, and sexual functioning are abundant in the literature (e.g., Bronner-Huszar, 1971; Cohen & Wellisch, 1978; McCollum, 1978). Some of the intruding factors in this disruption include lowered self-esteem (Bronner-Huszar, 1971; Eisenberg & Goldenberg, 1966), increased anxiety (Bronner-Huszar, 1971; Gorzynski & Holland, 1979), death-related concerns and uncertainty about the future (Clapp, 1976; Cohen & Wellisch, 1978; Gorzynski & Holland, 1979; Kagen-Goodheart, 1977; Spinetta & Maloney, 1975), and disruption of defense mechanisms (D'Angio & Ross, 1981; Hackett & Weisman, 1969; O'Neill, 1975). In their description of case reports, Cohen and Wellisch (1978) depict the surviving patient and family as thrown into a state of chronic catastrophe--a psychosocial "limbo"--where current relationships and future plans are constantly off balance because of disease uncertainty. Their observations were based upon patients _recently_ completing treatment, and so the question of possible abatement of this feeling of being in limbo remains unanswered.

There have been some systematic empirical studies of cancer patients in the six-month period following diagnosis and treatment. Weisman and Worden (1976-77) studied 120 cancer patients, 18 of whom were Hodgkin's patients, over a 100-day period following diagnosis. They found that as treatment progressed, the young adult patients viewed their cancer more as a threat to their life plans (career, marriage, family) than as a direct threat to their life. They identified a 100-day post-diagnosis period, called the "existential plight," in which fears of abandonment, loneliness, loss of control, pain, panic and the unknown were high. These concerns lessened most quickly in the Hodgkin's disease (_N_ = 18) and breast cancer (_N_ = 37) patients, as compared to lung (_N_ = 23), colon (_N_ = 23), and melanoma (_N_ = 19) patients. This observation of different peak distress points for different cancer sites signified the importance of studying disease sites separately rather than under one general rubric of cancer patients.

Perhaps the most comprehensive short-term follow-up of treated cancer patients has been done at the New York University Medical Center (Gordon, Freidenbergs, Diller, Hibbard, Levine, Wolf , Ezrachi, & Lipkins, 1979). The authors studied 308 breast, lung and melanoma patients at four points in time over a six-month period (point of diagnosis, point of hospital discharge, three months after discharge, and six months after discharge). Assessment was done by semi-structured interview (Problem Oriented Record) and a short battery of psychological tests. In their sample, the main problem at diagnosis was worry about disease, whereas by the time of hospital discharge it had shifted to difficulties with negative affects such as depression, anxiety and anger. At three- and six-month follow-up, problems were more widely distributed (and reduced in intensity) across the following areas: physical discomfort, concern about treatment, mobility, finances, family/marital problems, social problems, worry about disease, negative affects, and disturbed body image.

Many investigators have attempted to identify patients at high risk for maladaptation to cancer treatment and survival. Two general approaches to this have been the study of defenses or coping style in good versus poor adjusters, and empirical efforts to correlate pre-treatment psychological test scores with post-treatment adjustment. The first approach has, in almost every investigation, identified the ubiquitous and highly adaptive nature of denial during the treatment and early post-treatment periods (Chodoff, Friedman, & Hamburg, 1964; Hackett & Weisman, 1969; Penman, 1979). However, the functional adaptability of denial lessens as remission extends, and some investigators have identified actual increases in psychological distress and disturbance in the off-treatment period, presumably due to the lifting of denial and exposure of the denied affects of depression, anxiety, and hostility (O'Neill, 1975; Spinetta & Maloney, 1975).

It has been suggested that the ability to ultimately externalize previously denied affects is associated with longer survival, possibly due to the release of distress. Derogatis, Abeloff, and Melisaratos (1979) studied 35 women with metastatic breast cancer, and found that those women who lived one year or longer had <u>higher</u> psychological symptom profiles and <u>higher</u> levels of dysphoric affects than those who died within one year, on the SCL-90-R, Affects Balance Scale, and the Global Assessment Scale. A negative correlation between psychological distress and likelihood of recurrence was also documented in melanoma patients (Rogentine, VanKammen, Fox, Rosenblatt, Docherty, & Banney, 1978). Perhaps, then, the unleashing of previously constrained emotionality may not only be of high incidence in the cancer survivor, it may actually be a partial prophyllactic against relapse through some cathartic mechanism of stress reduction. This hypothesis would be consistent with the claim by other investigators that the best mechanism of coping with cancer and survival is not blind (unconscious) denial, but a conscious suppression of negative affects only after they are acknowledged and felt (Koocher & O'Malley, 1981; Weisman & Worden, 1976-77). These "suppressors," then, can be described as people who are able to put their worries aside and go on with their lives while in crisis. The survival period would then be a time for further integration and resolution of that which had previously been suppressed.

The above formulation of optimal coping over time is one which has received widespread empirical support. However, there are some data which are inconsistent with this. These would include accounts that psychological distress tends to drop over time (D'Angio & Ross, 1981), and that longer survival times have also been associated with patients who have been able to maintain smooth relationships with family and friends (Weisman, 1975).

The second general approach to studying post-treatment psychosocial difficulty is the attempt to identify patients at high risk for psychological distress in the post-treatment period with the use of pre-treatment parameters. Using examiner ratings of post-treatment distress in patients six months off-treatment, Weisman and Worden (1977) were able to account for 40-60% of the variance of psychological distress with knowledge of disease stage and prognosis. That is, medically sicker patients were significantly more distressed six months off-treatment. This is contrasted to studies which have found little (Gordon et al., 1979) or no (Myerowitz, Sparks, & Spears, 1979) relationship between disease or treatment severity and post-treatment distress. Some studies (Morris, Greer, & White, 1977; Schonfield, 1972) have found pre-treatment anxiety and depression to be better predictors than disease or treatment severity, of post-treatment distress in patients less than one year off-treatment.

A comprehensive study by Sobel and Worden (1979) followed 133 cancer patients, including 20 with Hodgkin's disease, over a period of six months. They found pre-treatment MMPI scale scores (especially on the "neurotic triad" of hypochondriasis, depression, and hysteria) accounted for 41% of the overall variance of the dependent measures of emotional distress. Dependent measures included the Profile of Mood States' Index of Vulnerability, Inventory of Current Concerns (six problem areas), and actual number of physical symptom complaints.

They were able to correctly place 75% of their 133 patients into high or low distress groups, on the basis of pre-treatment MMPI scores.

This concludes the review of the literature in this subsection: studies on cancer patients' difficulties with smooth return to premorbid lifestyle. The focus of this subsection was on the treatment and early post-treatment periods. Psychosocial disruption and difficulty in the treatment and reentry periods has been extensively documented. Not only has a relatively high prevalence of such disruptions as negative affects, low self-esteem, and psychosocial dysfunction been established, some investigators have successfully identified poorer post-treatment copers on the basis of pre-treatment symptomatology and personality profile. There is little doubt that the six-month period after treatment is difficult for a great many patients. The focus of study in this group of patients tends to be on the identification of high risk patients and determination of correlates to psychosocial dysfunction. Psychosocial research is not so advanced in patients who are farther off treatment, however.

The review will now turn to a discussion of studies which have addressed longer-term issues in cancer survival. To a great extent, this division of the review is artificial in that the process of adaptation is believed to begin with diagnosis (if not onset of first symptom) and move continuously through life. What follows is a summary of available literature on psychological adjustment to cancer, limited to the period of disease-free survival of longer than six months.

Studies on Psychological Adjustment to Long-Term Survival from Cancer

Of greatest relevance to the present study is that body of research which has examined long-term adjustment to survival from cancer. Since so little research has been done on Hodgkin's disease patients in particular, the review will include other more commonly studied populations: mixed diagnostic groups and breast cancer patients.

Psychosocial studies of cancer survival: Mixed diagnostic groups. Many investigators have reported quite favorable overall psychological adjustment to successful cancer treatment (Brown, Haddox, Posada, & Rubio, 1972; DeRugna & Buchheim, 1979; Holmes & Holmes, 1975). In a study examining the prevalence of general post-treatment difficulties, Iszak, Engel, and Medalie (1973) surveyed 345 patients, 91 of whom were considered "cured" at the time of assessment. They found, predictably, that the cured subgroup had the greatest need for vocational services and the lowest need for medical services. Problems identified in the cured group, as assessed by the authors' "Ability Index" questionnaire, were continued difficulty with physical stamina and with the "psychological trauma" posed by diagnosis and treatment. Need for social services, including both practical assistance and psychotherapeutic intervention, was acknowledged in 33% of 345 patients (Iszak, Engel, & Medalie, 1973).

A similar prevalence study of psychosocial problems acknowledged by 810 patients off-treatment for an average of 2.5 years found 93% of them still struggling with problems of fatigue (Greenleigh Associates, Inc., 1979). Of this 93%, one in five viewed the fatigue to be incapacitating. The authors speculate that, in the absence of any legitimate physiological reason for this high figure, it may provide indirect evidence for lethargy as a depressive equivalent in this population. All patients were over 45, 70% were women, and around half had either breast or uterine cancer. Patient historical accounts revealed an apparent six-month lag from treatment cessation to the development of depressive symptoms, again suggesting gradual relaxation of defenses (cf. O'Neill, 1975; Spinetta & Maloney, 1975). Sexual dysfunction was the most frequently cited marital problem (47 of 567 married subjects). Other problems included spouse anger or fear of cancer, financial difficulty, spouse withdrawl or spouse alcoholism. While 23% complained of deterioration in their family role satisfaction, 35% claimed their situation had improved as a result of their cancer experience. Health and life insurance readjustments were problematic for 24% of the patients. The percentage of patients employed dropped significantly, from 54% (premorbid level) to 47%.

The areas of work adjustment and work discrimination have received a good deal of attention in the literature. The available evidence on work discrimination is split between reports of little or no overt or covert discrimination toward the cured cancer patient (Reynolds, 1977; Stone, 1975), and assertions of both outright (Feldman, 1978) and subtle (American Cancer Society, 1976) work and hiring discrimination. In the American Cancer Society study, out of 130 of the most employable recovered cancer patients (age 25-50, employed at the time of diagnosis, and skilled), 22% reported one or more job rejections. Many on-the-job reports of subtle mistreatment such as hostility from co-workers, unnecessary transfers to encourage resignation, lack of salary advances and health benefit rejection were common (American Cancer Society, 1976).

Research on work adjustment in post-treatment patients also delivers mixed results. For example, Gordon and colleagues found one-third of 136 patients off treatment to be experiencing vocational adjustment difficulties (Gordon, Freidenbergs, Diller, Hibbard, Levine, Wolf, Ezrachi, & Francis, 1977), while Wheatley and others found 74 off-treatment cancer patients to be no different from other employees at the Metropolitan Life Insurance Company in absenteeism, turnover, job performance, or insurance costs (Wheatley, Cunnick, Wright, & Van Keuren, 1974). Not one of the 74 patients was fired for any reason. They had been off treatment for a range of one month to 25 years. One explanation for this difference between study findings in the area of work adjustment could be the method of data collection: Gordon and colleagues used patient self-report while the Wheatley et al. study used employer records. It could be, therefore, that the patient experiences a sense of difficulty in adjusting which is not easily detected by gross measures of work performance kept by employers. Alternately, it could be that the patients truly are adjusting well, and their subjective sense of maladjustment might represent a more non-specific problem of general distress.

Schonfield (1972) has attempted to predict those patients who will experience post-treatment work readjustment difficulty. In his study of 42 male and female patients, using 63 items of the MMPI and an anxiety questionnaire given before starting treatment, he demonstrated that pre-treatment anxiety (especially about situational concerns) and a low morale loss score on the MMPI were good predictors of later difficulty returning to work. All but nine of 42 patients returned to work within nine months of treatment. Stage of disease and severity of treatment were not effective predictors of successful return to work.

In a more general study, Mages and Mendelsohn (1979) examined 60 patients with various cancer sites, most of whom had received a radiation-only treatment regimen. Some of these patients were three- to six-year survivors. Their findings indicated marked increases in self-image, values and physical capacities over time, but little change in level of dysphoria on the Gough-Heilbrun Adjective Checklist. They also reported improvements in distractibility, absent-mindedness and concentration, as well as an increase in focus on home and family concerns over time. Women were more able than men to preserve their sense of self-esteem over time off treatment. The authors comment that in their young adult patients, the cancer experience impeded the development of their self-sufficiency and resulted in delay and disruption of the smooth establishing of adult roles.

A study by Kennedy, Tellegen, Kennedy, and Havernick (1976) examined 22 advanced cancer patients (various sites), aged 20-69, 5-20 years off treatment. They found the men to have a significantly higher mean stress-reactivity level on the Differential Personality Questionnaire. Women had a higher mean social closeness score. That is, women particularly valued close and friendly personal relationships, while the men appeared at higher risk for post-treatment distress.

Interestingly, all cancer patients in their study showed a greater appreciation for life, people, time, and interpersonal relationships when compared to matched samples of chronic diabetes patients and normal (healthy) controls. They were less concerned than the comparison groups with the "non-essentials" of life. The authors conclude that cancer, when met with successful treatment, is a good catalyst for character development. They base this conclusion on the finding of generally positive adjustment without significant psychosocial distress, as measured by physician assessment, semantic differential ratings, the Differential Personality Questionnaire, and unstructured interview (Kennedy et al., 1979).

A final psychosocial study of diagnostically mixed cancer patients assessed 20 patients aged 29-78, 1-33 years post-diagnosis (Shanfield, 1980). Based upon data from unstructured interviews, the author concluded that fear of cancer, then fear of significant object loss, were the numbers one and two concerns, respectively, of the surviving cancer patient. Mild depression was detected in 25% of the sample. Physical vulnerability was named as a consequence related to the fear of recurrence. Shanfield also identified a sense of existential resolution with death which the successfully treated patient feels. With this sense of resolution comes a heightened sense of life appreciation, according to Shanfield's data.

Psychosexual studies of cancer survival: Mixed diagnostic groups. In accord with other studies (Greenleigh Associates, 1979; Shanfield, 1980), Sutherland (1960) identified the fear of rejection as the main source of anxiety in the off-treatment cancer patient.

According to Sutherland, this fear of rejection or abandonment can be expected to show itself through sexual dysfunction. Golden and Golden (1980) have suggested that the frequently observed desexualization of the cancer patient is often an interpersonal (rather than personal) dysfunction in that it is often the healthy partner who initiates, or at least actively colludes with, disengagement. Lamb and Woods (1981) have discussed the public image of cancer which, despite the many recent treatment advances, is still one of a terminal or chronic passive illness. This would militate against an unconflicted acceptance of the recovered patient's return to an active, vigorous sex life.

Many authors (e.g., Grinker, 1976) have emphasized the primary influence of psychological rather than physiological causes for impotence and general sexual dysfunction in cancer patients. One piece of evidence for this assertion is that sexual dysfunctions often continue well into the post-treatment period, virtually nullifying the possibility of drug- or disease-related etiology. These reported post-treatment dysfunctions have been attributed to decreased libido, concern over performance, defective body image, fear of rejection, gender identity disturbance, fear of disease contagion, and depression (Chapman, 1982; Grinker, 1976; Schain, 1982; Sutcliffe, 1979; Wise, 1978).

The bulk of the writing in the area of sexual dysfunction in cancer patients of mixed diagnostic categories has been based upon case reports and clinical experience. The absence of systematic empirical attention to this area is striking. However, there have been careful studies of sexual dysfunction in the specific diagnostic classes of Hodgkin's disease and breast cancer patients. These will be discussed later, along with psychosocial studies of those specific groups.

Before discussing breast cancer and Hodgkin's disease patient studies in particular, one empirical study of male and female cancer patients (various sites) in treatment will be described, because it holds relevance to one of the study's aims. This study explored communication and fulfillment of affectional needs in 36 patients and their spouses (Leiber et al., 1976). Based upon the results of an Affectional Needs and Behavior Scale and upon interview material, the authors concluded that desire for sexual intercourse decreased in 37% of all patients, while the desire for non-sexual physical closeness increased in 49% of patients. Women patients were more likely to have their affectional needs met than men. They were also the most depressed of the four groups of subjects (male patients, female patients, husbands and wives). An interesting finding which holds direct relevance to the current study was that male patients experienced the greater disparity of needs and alteration of sex roles in relation to their wives, as compared to female patients. Therefore, they had greater potential for marital tension and discord. The authors speculate that it is more difficult for the young adult man than the young adult woman to assimilate the passivity and dependency of the patient role. The young man's burgeoning sense of competence may be more acutely threatened by the impact of untimely disease.

This is one reason for selecting men as the focus of study in this investigation: they may be at higher risk for psychosocial and psychosexual maladjustment.

In summary of previous investigations of cancer survival, many of the studies on mixed diagnostic groups have been quite extensive with regard to sample size, but very global when one considers the type of inquiry. Previous studies have tended to focus on the presence of general depressive symptomatology and quality of life as reflected in self-report. Findings have been inconsistent, surely due in part to differing methodologies and unclear criteria for "disturbance." Research reports on the impact of cancer in the survival period have run the full gamut of conclusions, from positive character growth through no significant change to heightened risk of depression, anxiety, fatigue, work maladjustment and discrimination, and interpersonal difficulties. Reports of post-treatment psychosexual dysfunction in the general cancer population have been more impressionistic and superficially documented than carefully empirical in their basis. Systematic exploration of this particular area is notably lacking in the general psychosocial oncology literature.

Psychosocial and psychosexual studies of cancer survival: Breast cancer patients. The fact that breast cancer, if detected early, has long been amenable to successful treatment with combined surgery and radiotherapy has led to extensive psychological study of survival in this particular disease group. The insult of cancer upon such a culturally valued sexual body part can have potentially far-reaching psychosexual ramifications (Derogatis, 1980). The following studies will only highlight the many studies in the area of psychological adjustment to breast cancer survival. Characteristic of research in this area, these studies reveal a pattern of mixed results.

Eisenberg and Goldenberg (1966) tested 252 breast cancer patients immediately after mastectomy and 18 months later. They found persistent decrements in self-esteem and an actual drop over time in the percentage of patients who held a positive attitude toward their future, from 54% down to 39%. This drop may again represent a lifting of defenses in the recovery phase of survival.

In an extensive mail survey of 826 breast cancer patients randomly selected from the Memorial Hospital registry of 5,472 patients treated for breast cancer between 1949-1962, 84% of survivors off treatment for five or more years had, by their own criteria, fully resumed their premorbid lifestyles (Schottenfeld & Robbins, 1970). Many of this group (14%) said that it took them over six months post-treatment to do so. This suggests that around 30% of these patients failed to successfully resume premorbid functioning within six months of completing treatment. Comparing five-year survivors to 10- and 15-year survivors, they found that severity of disease did tend to slow down the process of return to earlier occupational status: Within the five-year group only, ratings of women with regionally spread disease were lower than those with localized disease.

A very well-controlled study has compared 134 breast cancer patients, most of whom were five or more years off treatment, to 139 age-matched controls and 121 neighborhood controls (Craig, Comstock,

& Geiser, 1974). All were given the same 28-item general health and quality of life questionnaire. There were no significant differences in level of employment, attitude toward life, view of the future, leisure activities, or psychiatric symptoms. The only differences between groups which reached significance were that the cancer patients rated their current health as poorer and rated themselves as more physically disabled than the two control groups. Both of these differences have clearly realistic bases, and were therefore not seen as signs of maladjustment in these women.

A prospective investigation, using the "Ability Index" from an earlier study (Iszak & Medalie, 1971), followed 221 breast cancer patients over a three-year off-treatment period (Iszak, Feller, Brenner, Medalie, & Tugendreich, 1975). All patients, including 90 with stage I and 131 with stage II disease, had the same treatment: Radical mastectomy plus radiation. One year after treatment, 201 (91%) were still living; 167 (75%) were still alive at three years. General problems surveyed by the Ability Index included subjective complaints about medical treatment, reduced ability to support themselves, change in relationships with family and friends, and emotional well-being vis-a-vis health concerns. Comparing survivors one year off treatment to themselves three years off treatment, they identified a slight drop (21% to 15%) in patients with ambulatory limitations, increases in sexual disturbances over time (12% to 18% frequency), improvement in ability to support oneself financially over time (30% disabled to 20% disabled), and a slight drop in social (extrafamilial) contact over time. There was no change noted in familial relationships over time, lending support to the common notion that one aspect of adpatation to cancer survival entails some withdrawal from the milieu of friends and increased focus on family togetherness. Patients at both times of assessment demonstrated difficulties in lack of self-confidence, fear, frustration, and anger about the future, at a frequency of approximately 25%.

The results from this comprehensive study (Iszak et al., 1975) reflect a mixed picture of adaptation. There is some indication of life enhancement from the cancer experience, but somewhat more evidence for mild psychosocial disruption. Another study has supported this figure of 25% psychological distress after one year off treatment, but asserts that this figure drops over the following four years (Maguire, 1976). Morris, Greer, and White (1977), on the other hand, reported that 30% of their 69 breast patients were psychologically distressed one year after treatment, and that this figure did not drop in the second year. They used psychological tests and a different structured interview, so the different measures and different criteria for distress (self-report vs. test scores) could explain why one group found this drop and the other did not. The study by Morris and colleagues compared 69 breast cancer patients to 91 women with benign breast disease both cross-sectionally and longitudinally. Two years after diagnosis and surgery, 83% of the cancer group and 76% of the benign group had successfully resumed premorbid work and marital functioning.

A final study to be reported here, exemplary of research in breast cancer survival, examined 49 post-mastectomy patients four years after treatment (Woods & Earp, 1978). Through structured interview they determined that women who complained of more physical symptoms during and after treatment were also those who were in greater psychological distress. Incidence of sexual dysfunction remained high four years off treatment for these women, and was related to marital discord. The authors conclude that social support (including family and social service assistance) has a buffering effect upon the psychosocial adjustment difficulties of the cured breast cancer patient.

Psychosocial and psychosexual studies of cancer survival: Hodgkin's disease patients. Very little has been done in the specific study of Hodgkin's disease patients off treatment. The greatest emphasis has been on psychosexual adaptation, since the known sterilizing effects of combination chemotherapy and radiation have led oncologists to be concerned about psychosexual dysfunction which might arise from this impairment. Once again, the research in this area has yielded mixed findings.

In conjunction with their initial trials of MOPP chemotherapy, Sherins and DeVita (1973) found 16 treated Hodgkin's disease patients to experience normal ejaculation in the face of abnormal spermatogenesis. In a larger study, 74 Hodgkin's disease patients were assessed an average of 27 months after treatment (Chapman, Sutcliffe, Rees, Edwards, & Malpas, 1979). Compared to a rate of 74% during treatment, 46% of all patients complained of decreased libido and sexual performance in the post-treatment period. Few of this 46% were subjectively distressed about their difficulty, however. Six of 54 men were rendered impotent. Four of these cases had no physiologic basis for their impotence.

In a related study, Chapman, Sutcliffe, and Malpas (1981) interviewed 47 male Hodgkin's patients about general quality of life and subjective personality changes as well as psychosexual dysfunction. Most of these patients were studied prospectively, from the pre-treatment period through treatment cessation. Twenty-one of them were post-treatment patients who made retrospective ratings of the treatment and survival periods. Half of all patients stated their libido had not returned to pre-treatment levels. They did, however, acknowledge a gradual increase in libido and general quality of life over the years while in complete remission. Other findings of the study included a tendency toward increase in violent behavior and irritability in the post-treatment period. Irritability, for example, was given as a "status quo" affect in 84% of patients recently off treatment, as opposed to 16% of pre-treatment patients. The authors concluded that the emotional response of a young man becoming ill may represent a particular vulnerability in that the dependency of illness and the sterilizing effect of treatment are decidedly "unmasculine" experiences which can challenge the smooth transition into adulthood (cf. Leiber et al., 1976).

In a larger study (Cunningham et al., 1982), 156 male Hodgkin's patients, ranging from 43-141 months off treatment, were interviewed. Most of them (112) were between the ages of 15-40. Using gross career criteria and patient comparisons of lifestyle changes contrasting retrospective pre-treatment ratings to current ratings, they concluded that nearly all of the sample had led "normal" post-treatment lives. Of 263 (male <u>and</u> female) patients, four had severe physical complications and only two displayed serious psychiatric disturbance (Cunningham et al., 1982).

Two other psychosocial studies with Hodgkin's disease patients also hold importance for the current study. The first was a mail survey of socialization skills in 30 adolescents an average of three years off treatment (Mitchell, 1982). Using the Aschenbach Child Behavior Checklist, the author found that adolescents with Hodgkin's disease did not show the predicted decrease in socialization abilities. Mitchell did determine that patients who had more severe disease, and therefore were subjected to more aggressive combined modality treatment, displayed lower activity levels than those who had less severe disease. This suggested some element of fatigue, or perhaps developmental lag, secondary to greater isolation from the peer group in recovered adolescents with later stage disease. All patients showed restriction in their drive for independence, presumably related to the dependency induced by the sick role (cf. Chapman et al., 1981; Leiber et al., 1976).

The final study relating specifically to Hodgkin's disease patients compared 37 Hodgkin's patients aged 18-45 to 28 young adult parents of leukemic children (Morrow, 1980). Morrow used the "PAIS," or Psychosocial Adjustment to Illness Scale (Morrow, Chiarello, & Derogatis, 1978). The parent group was shown to have greater overall psychological distress than the Hodgkin's group. Of the 37 Hodgkin's patients, 32 were off treatment for two or more years ($\underline{M}$ = 5.5 years). Morrow (1980) also found that both the parents and the 32 Hodgkin's patients more than two years off treatment had higher anxiety scores on the Gottschalk-Gleser (1969) Content Analysis Scale than the scale's normative sample. Unlike the parent group, however, the Hodgkin's patients did not score any higher than the normative sample on level of hostility.

To summarize, the research done with Hodgkin's disease patients specifically has often been superficial in its methodology and has produced inconsistent results. Some studies have identified reduced libido, fatigue, anxiety, irritability, and depression which linger on into the post-treatment period. Others have denied the presence of such problems.

While not strictly a study of Hodgkin's disease survivors, one final investigation will be discussed in this section. Koocher and O'Malley (1981) undertook an extensive investigation of childhood cancer survivors which offers data relevant to understanding the long-term adjustment difficulties of survivors of Hodgkin's disease as well as other childhood cancers.

The realization that no study had comprehensively assessed mental health or psychological adjustment in childhood cancer survivors, led Koocher and colleagues to initiate extensive investigation of this area (Koocher & O'Malley, 1981; Koocher, O'Malley, Gogan, & Foster, 1980; O'Malley, Koocher, Foster, & Slavin, 1979). Koocher and O'Malley's (1981) book, titled "The Damocles Syndrome," takes its name from the story of Damocles, who assertedly was forced to sit at a banquet in the court of Dionysus under a sword suspended by a single hair, to depict the precariousness of his fortunes. Such uncertainty is presented by the authors as the dilemma which all successfully treated cancer patients face during the initial years following treatment, if not for their entire lives.

Since the conceptualization and execution of Koocher and O'Malley's work has contributed greatly to the thinking behind the current investigation, it will be summarized in some detail. The book presents the results of their intensive examination of 117 childhood cancer survivors and a comparison group of 22 children with various chronic diseases. The children with cancer had either neuroblastoma, leukemia, osteosarcoma, non-Hodgkin's lymphoma, or Hodgkin's disease. Mean age at diagnosis was 5.5 years, and mean age at testing was 18. All children were at least five years post-diagnosis.

The authors of the study identified "uncertainty of survival" as the chief independent variable. Thus, they did not pay close attention to time off treatment or disease severity as potential factors. They did, however, compare different diagnostic categories to each other on some of the measures. Dependent measures were administered to all subjects and included Srole's (1962) Combined Adjustment Rating Scale, a standardized interview including mental status examination, Rutter and Graham's (1968) Standardized Psychiatric Interview (for the 7-12 year old subjects), the Wechsler Intelligence Scale's Information, Similarities and Vocabulary subtests, the Vineland Social Maturity Scale, Conte's (1975) Self-Rating Depression Scale, Conte's (1975) Death Anxiety Questionnaire, the Bendig (1956) short form of the Taylor Manifest Anxiety Scale, Bills' (1961) Index of Adjustment and Values (a self-esteem measure) and TAT cards 1, 3GF, 8BM, 13B, and 14 as well as Waechter's (1971) four drawings of hospital scenes. These nine stories of each participant were scored for content reflecting sadness, loneliness, individual reflection, and story resolution.

The principal (global) finding of their study was that 47% of 117 long-term survivors of childhood cancer showed some degree of adjustment difficulty as measured by the Combined Adjustment Ratings of two independent raters (interrater Pearson's _r_ = .85). This percentage was significantly greater than that for the smaller group of children with chronic illness. Within the cancer group, the highest incidence of adjustment difficulty was in the Hodgkin's disease subgroup (64%). The authors proposed two interpretations for this. One was that because this was the oldest subgroup of patients, it may indicate that psychosocial adjustment to childhood cancer is more problematic for older children and adolescents than for younger children. This makes intuitive sense in that the developmental tasks of adolescence are in direct opposition to the dependency which sickness and recovery engender. The second interpretation offered was that the more prolonged treatment which Hodgkin's disease patients receive by comparison to other childhood cancers may increase the sense of uncertainty and danger which the young patient experiences. A related issue is that many Hodgkin's patients receive splenectomies which can prolong immunodeficiencies. Successfully treated Hodgkin's patients may therefore be required to take antibiotics as immunotherapy long after treatment ends; an ever-present reminder of continued vulnerability.

In this same investigation (Koocher & O'Malley, 1981), no differences were found between the general cancer group and the chronic illness comparison group in verbal intelligence or social maturity. Likewise, cancer patients did not show elevated death anxiety, manifest anxiety, or depression. Self-esteem as measured by self-report was not significantly lower. Multiple regression analysis showed higher intelligence and higher socio-economic status to be good predictors of positive adjustment. As implied earlier, age at diagnosis was also a good predictor of positive adjustment, with younger patients faring better. Time since diagnosis, while not built into the hypotheses of the study, did show itself to be a good predictor of adjustment (the more time elapsed, the better). Disease severity did not.

Koocher and O'Malley conclude their book with a formulation of adaptation to cancer based upon their empirical findings and their review of the literature. They conclude that the "stress" of cancer is greatest at the point of diagnosis and initiation of treatment, and that it slowly diminishes over time, nearly reaching baseline at five years post-diagnosis. During the course of this decline, various events such as recurrence, symptom distress or death in the family can disturb the settling process and initiate elevations in stress. The patient, in a state of heightened vulnerability due to the protracted working through of the impact of cancer and its treatment, is likely to be more easily over-excited and distressed. This, according to the authors, is optimally dealt with through adaptive denial which is best described as a conscious suppression of feelings, and an increase in activity to counterbalance the passivity of illness. The almost universal use of denial, in 99% of patients (O'Malley et al., 1979), is again a powerful testimony to its effectiveness if not necessity.

Psychosocial and psychosexual studies of cancer survival: Summary. In general, the research on cancer survival, Hodgkin's disease patients included, has yielded mixed results. Quite often, protracted and exaggerated psychological symptomatology such as depression, anxiety, somatization, fatigue, and irritability have been reported. Evidence for significant psychosexual dysfunction, particularly as it is affected by body image and interpersonal concerns, has been presented. Psychosocial areas of occupational functioning and marital satisfaction have also been cited as problematic. On the other hand, there are investigators who deny the presence of significant psychosocial or psychosexual disruption in the cancer survivor. Some have even emphasized the positive, growthful aspects of having suffered through and endured the ordeal of successful cancer treatment. In some studies, both positive and negative effects have been known to coexist, possibly exerting separate influences upon adaptation.

There are several problems with the experimental methodology to date which may contribute to the inconsistencies and inconclusiveness of the results outlined. First, investigations have differed greatly in their use of control or comparison groups. Some have used no comparison group at all, opting to compare their findings to established base rates, normative data, or mere common sense. Second, measurement of dependent variables has often been global, and has tended to rely upon non-standardized interview responses rather than structured questionnaires or more in-depth projective tests. A third problem with past research is that the groups being studied have often been quite heterogeneous. Many studies have neglected to differentiate diagnostic categories within the cancer variable. Of those which have, efforts to isolate effects of disease stage, treatment severity, or length of time off treatment have usually been minimal or non-existent. Therefore, more extensive study of cancer survival, focusing on specific diagnostic groups, specific treatment regimens, and clearly delineated survival periods seems necessary to help clarify the current confusion about the psychosocial aspects of cancer survival.

Hypotheses of the Study

The present study attempts to identify psychosocial and psychosexual liabilities which may accompany survival from successful cancer treatment. Unlike most other studies, it limits itself to the study of one diagnostic group, Hodgkin's disease, so that the variables of diagnosis and treatment may be held relatively constant. Also, unlike other studies, it focuses exclusively upon young adult men, a group of patients identified in the literature as at high risk for psychosocial and psychosexual distress. The selection of a "good prognosis" cancer minimizes the realistic threat to survival so that the study of patient uncertainty will be, as much as possible, a psychological one.

The three independent variables of interest are: 1) history of Hodgkin's disease and treatment ($\underline{N}$ = 60 patients vs. $\underline{N}$ = 20 age-matched non-patients); 2) severity of illness and treatment ($\underline{N}$ = 30 early stage vs. $\underline{N}$ = 30 late stage patients); and 3) length of time off treatment ($\underline{N}$ = 30 less than 24 months vs. $\underline{N}$ = 30 more than 30 months off treatment). This is the first known study which systematically examines the combined contribution of these variables to adaptation in cancer survival.

Guided by the literature just reviewed, the following hypotheses were generated prior to the study:

1. Patients will appear more disturbed than non-patients on self-report measures of psychosexual functioning, psychological symptom distress, self-esteem, death anxiety, and coping adequacy, and on interview ratings of global adjustment. Because of conflicting studies reporting both increased need for interpersonal closeness and decreased ability to achieve this, it was hypothesized that patients would show different (perhaps higher, perhaps lower) capacity for intimacy than non-patients.

2. On semi-structured interview, patients will show greater difficulty in work adjustment, a heightened appreciation for life, and higher self-ratings of overall quality of life than the non-patient sample.

3. Late stage patients will appear more disturbed than early stage patients on self-report measures of psychosexual functioning, psychological symptom distress, self-esteem, death anxiety, and coping adequacy, and on interview ratings of global adjustment. They should also be different than early stage patients in intimacy capacity (motivation).

4. On semi-structured interview, late stage patients will show greater difficulty with work adjustment, a lower appreciation of life, and lower self-ratings of overall quality of life than the early stage patients. Late stage patients are also expected to show greater subjective disturbance in physical stamina, sleep, eating habits, and

concentration abilities (possible depressive equivalents). Additionally, they should have greater difficulty with the prolongation of conditioned nausea and anxiety during the off-treatment period.

5. Patients recently off treatment will appear more disturbed than those off treatment for longer periods of time, on self-report measures of psychosexual dysfunction, psychological symptom distress, self-esteem, death anxiety, and coping adequacy, and on interview ratings of global adjustment. They also should be different from patients distantly off treatment in capacity for intimacy (intimacy motivation).

6. On semi-structured interview, patients recently completing treatment should show greater difficulty with work adjustment, a lower appreciation for life, and lower self-ratings of overall quality of life than those patients distantly off treatment. Patients recently completing treatment are also expected to show greater subjective disturbance in physical stamina, sleep, eating habits, and concentration ability (possible depressive equivalents). They should also acknowledge a higher incidence of conditioned nausea and anxiety during the off-treatment period.

METHOD

Subjects

The study sample consisted of 80 men ranging in age from 21 to 46 years at the time of assessment. Sixty of these men were Hodgkin's disease patients at Memorial Sloan-Kettering Cancer Center, off all treatment and showing no clinical evidence of disease for at least six months. The other 20 participants were age-matched healthy volunteers who had never suffered any life-threatening physical illness or debilitating medical treatment.

Patients potentially eligible for study were Memorial Hospital male Hodgkin's disease patients between 18 and 50, who had received their diagnosis before age 45. With this as a starting point, treatment protocol records of 151 patients listed as at least six months off treatment were reviewed. In this review, 33 patients were excluded for the following reasons: recent relapse (15), death (5), formal psychiatric history which predated cancer diagnosis (3), serious (life-threatening) physical illness in addition to cancer diagnosis (2), and non-fluency in English (2). "Formal psychiatric history" was defined as prior hospitalization or outpatient medication, but not outpatient psychotherapy alone. Of the remaining 118 patients, 14 were placed on low priority eligibility because they were between 24 and 30 months off treatment. This was done to help separate patients more cleanly into the two time-off-treatment cells. None of these 14 patients had to be approached for study.

Patients were placed into one of four mutually exclusive cells for analysis. The design was essentially a 2 (disease stage) by 2 (time off treatment) factorial layout with an appended comparison group (see Figure 1). The disease stage variable was broken down into "EARLY" (IA, IB, IIA, IIIA) and "LATE" (IIB, IIIB, IVA, IVB), as is the custom at Memorial Hospital. The time off treatment variable was broken down into "RECENT" (6-24 months off treatment) and "DISTANT" (over 30 months off treatment). The combination of these two factors resulted in four patient groups: Early stage recently off treatment (ER); early stage distantly off treatment (ED); late stage recently off treatment (LR); and late stage distantly off treatment (LD).

From the pool of 104 eligible patients, prospective participants were recruited either by phone or in person when they came in for their check-up. The last 10 patients were carefully selected to ensure equal cell sizes. Of 69 patients asked, 62 agreed to participate. Six of the seven refusals came from men who stated that they would prefer not to be reminded of the treatment experience. The seventh refuser would not say why he declined. Two of the 62 patient participants were excluded from all analyses because they withdrew themselves from the study midway through their session.

The age-matched non-patient group was subjected to the same background inclusion criteria: age 20 to 46, absence of formal psychiatric history, absence of life-threatening physical illness, and fluency in English. Sixteen of them were either friends (12) or relatives (4) of the patients. This method of recruitment through the patient sample was chosen with the dual goal of informal matching

		DISEASE STAGE	
PATIENT GROUP		Early (IA,IB,IIA,IIIA)	Late (IIB,IIIB,IVA,IVB)
TIME OFF TREATMENT	Recent (6-24 mo.)	*N* = 15	*N* = 15
	Distant (over 30 mo.)	*N* = 15	*N* = 15
COMPARISON GROUP (non-patients)		*N* = 20	

FIGURE 1

Study Design (*N* = 80)

by similarity and to reduce the potential bias of volunteerism. After canvassing the entire sample of patients for volunteers, four comparison participants were still needed. These were obtained through extra-hospital contacts. The interviewer knew none of them personally.

Table 2 contains the demographic and socioeconomic characteristics of the sample. The apparent equivalence across the five groups on race, marital status, religion, family income bracket, and presence of children has been confirmed by non-significant χ^2 tests of statistical dependence. The only variable which differed significantly across cells was the Hollingshead Two-Factor Index of Social Position (Hollingshead, 1957), $\underline{F}(1,74) = 3.19$, $\underline{p} < .05$. This Two-Factor Index combines education (weight = 3) and occupation (weight = 5) into an estimate of social position. Mean comparison determined that the non-patient group had a somewhat higher social status than the combined patient sample, and the "Late Recent" patient group was somewhat lower than the other three patient groups.

Returning to the patient sample, all but four were treated according to one of the four Memorial Hospital treatment protocols discussed in the literature review. Of these 56 patients, 29 (52%) were treated with combined MOPP and involved field (local) radiation, 16 (28%) were treated with eight-drug chemotherapy (MOPP/ABDV) and local radiation, six (11%) with 10-drug chemotherapy (MOPP/ABV/CAD) and local radiation, and five (9%) with MOPP and local radiation followed by 8- or 10-drug chemotherapy and local radiation after relapse. The other four patients were treated before these protocols existed. Two received radiation alone, and two were treated with MOPP chemotherapy alone.

The mean time off treatment for the patients in the two "recent"

Table 2

Socio-Demographic Characteristics of the Sample

Variable	Patients				Non-Patients	Total
	Early Recent (*N*=15)	Early Distant (*N*=15)	Late Recent (*N*=15)	Late Distant (*N*=15)	(*N*=20)	(*N*=80)
AGE	*M*=31.5 *SD*=7.0	*M*=32.0 *SD*=7.8	*M*=30.5 *SD*=7.6	*M*=32.5 *SD*=5.0	*M*=29.4 *SD*=5.2	*M*=31.1 *SD*=6.5
RACE						
white	14	14	14	14	20	76
hispanic	1	1	1	1	0	4
MARITAL STATUS						
single	7(46%)	6(40%)	8(53%)	3(20%)	11(55%)	35(44%)
married	8(53%)	8(53%)	6(40%)	11(73%)	8(40%)	41(41%)
sep./div.	0(0%)	1(7%)	1(7%)	1(7%)	1(5%)	4(5%)
CHILDREN						
yes	6(40%)	6(40%)	7(47%)	4(27%)	5(25%)	28(35%)
no	9(60%)	9(60%)	8(53%)	11(73%)	15(75%)	52(65%)
RELIGION						
Catholic	10(67%)	8(53%)	8(53%)	8(53%)	12(60%)	46(57%)
Protestant	1(7%)	6(40%)	5(33%)	3(20%)	4(20%)	19(24%)
Jewish	4(26%)	1(7%)	1(7%)	4(27%)	4(20%)	14(18%)
none	0(0%)	0(0%)	1(7%)	0(0%)	0(0%)	1(1%)
INCOME BRACKET[1]						
\$0-10,000	1(6%)	2(13%)	4(27%)	0(0%)	2(10%)	9(11%)
\$10-20,000	4(27%)	3(20%)	3(20%)	5(33%)	4(20%)	19(24%)
\$20-30,000	4(27%)	3(20%)	7(47%)	2(14%)	4(20%)	20(25%)
\$30-50,000	4(27%)	6(40%)	1(6%)	3(20%)	7(35%)	21(26%)
over \$50,000	2(13%)	1(7%)	0(0%)	5(33%)	3(15%)	11(14%)
HOLLINGSHEAD INDEX	*M*=45.6 *SD*=12.5	*M*=40.4 *SD*=12.3	*M*=37.7 *SD*=12.1	*M*=48.9 *SD*=14.2	*M*=50.6 *SD*=11.2	*M*=45.1 *SD*=12.4

[1] Annual family income

groups was 13.2 months (11.8 months for late stage patients and 14.6 months for early stage patients). The mean time off treatment for the two "distant" groups was 55.4 months (50.7 months for late stage patients and 60.1 months for early stage patients). Within the time off treatment variable, differences across stage were not significant for both comparisons.

Materials

The dependent measures were organized into three categories: patient responses and ratings in interview, objective self-report measures, and experimenter ratings. These three categories will be described separately.

Interview Ratings and Responses: A Revised Problem Oriented Record

The Problem Oriented Record (POR) is a structured clinical interview which surveys 12 areas of life performance: problems with medical treatment, hospital service, mobility and housework, vocational problems, financial, family and social problems, worries regarding disease, and problems with affect, body image, and communication (Gordon, Freidenbergs, Diller, Hibbard, Levine, Wolf, Ezrachi, & Lipkins, 1978).

Each problem is scored for two components: problem existence (yes or no) and severity weighting of a problem (1-10 scale). The interview constructors selected this format because it provided specific scores for known problem areas of the cancer patient, and also lent sufficient flexibility to allow patients to "talk through" any uncomfortable feelings aroused by the interview. The POR has been demonstrated as useful with three separate cancer diagnoses: breast, lung, and melanoma (_N_ = 136).

Because POR was designed for use with cancer patients currently in treatment and only recently off treatment, substantial revision of the record was necessary. Some treatment-relevant questions were omitted, many questions were reworded to accommodate the sample, and some questions were added because they were believed to hold special relevance for the surviving patient (e.g., "Do you feel that you appreciate life more fully than you did before your illness?"; "How worried are you about having a recurrence?"). Appendix A shows the revised version of the POR used in this study.

Self-Report Measures

Derogatis Sexual Functioning Inventory (DSFI). The DSFI (Derogatis, 1975, 1978) is a 256-item inventory broken down into 11 subscales of psychosexual and psychological functioning. Nine of these scales (information, experience, drive, attitudes, gender role, fantasy, body image, satisfaction) tap sexual domains and the other two (psychiatric symptoms and affects balance) measure psychological domains which correlate with sexual functioning. The eight scales designated as relevant to this study were drive, gender role, fantasy, body image, satisfaction, global satisfaction, psychiatric symptoms, and affects balance. High scores on the drive, fantasy, satisfaction, global satisfaction, and affects balance subscales are associated with positive adaptation, or low impairment. The reverse is true of the body image and psychiatric symptoms subscales, where high scores reflect high impairment. A high gender role score indicates hypermasculinity, and a low score, hyperfemininity (in men). Appendix B shows the DSFI.

Internal consistency and test-retest reliability coefficients of the primary symptom dimensions are generally quite high, ranging from .56 to .97. Construct validity was demonstrated (N = 380) by principal components analysis, separating normals from known sexual dysfunctioning patients, using subscale factors to account for 52% of the variance. Discriminant function analysis achieved a 77% hit rate using the same sample of 380 (Derogatis & Melisaratos, 1979).

Brief Symptom Inventory (BSI). The BSI is a delineated version of the psychiatric symptoms subscale of the DSFI. This 53-item index (Section V of the DSFI) is a shortened form of the more familiar Symptom Check List-90 (SCL-90). Psychiatric symptoms subsumed under nine dimensions (somatization, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and a psychoticism) are rated by the participant on a 5-point Likert-type scale of intensity for the time period of the past two weeks by the participant. There are also summary scores of global severity of symptoms (total score ÷ 53), positive symptom total (total # of symptoms endorsed), and positive symptom distress index (average rating per symptom endorsed). Internal consistency (N = 719) and test-retest reliability (N = 60) coefficients for the nine dimensions and three global indices range from .68 to .91 (Derogatis & Spencer, 1982). Concurrent validity with the SCL-90 has been shown in a sample of psychiatric outpatients (N = 500) through correlation coefficients above .90 for all dimensions and indices. Convergent validity with the MMPI was demonstrated with 209 symptomatic volunteers (Derogatis & Spencer, 1982). The dimensions relevant to this study are somatization, interpersonal sensitivity, depression, phobic anxiety, paranoia, hostility, anxiety, global severity of symptoms, and positive symptom total.

Impact of Events Scale (IES). The IES is a 15-item measure of response to stressful life events along two constructs, intrusion and avoidance (Horowitz, Wilner, & Alvarez, 1979). The scale designers have found it useful in studying a person's response to the same traumatic event over long periods of time. Each item describes a reaction to the identified stressor (in this study, the diagnosis of cancer) which the subject endorses as present or absent along a weighted 4-point scale, with "0" = not at all, "1" = rarely, "3" = sometimes, and "5" = often. A high score is thus associated with high distress. Internal consistency (.78, .82) and test-retest (.89, .79) reliability of the intrustion and avoidance scales, respectively, were amply demonstrated on a sample of traumatized outpatients suffering from post-traumatic stress syndromes ($N = 66$). Construct and discriminant validity as well as test sensitivity were demonstrated in comparing this high distress group to 110 normal medical students recently after their first exposure to cadaver dissection, $F(1,172) = 212.1$, $p < .0001$ for intrusion and $F(1,172) = 73.0$, $p < .001$ for avoidance (Horowitz et al., 1979).

Rosenberg Self-Esteem Scale (RSES). The RSES is a 10-item inventory of self-esteem (Rosenberg, 1965). It is intended to measure the more conscious "self-acceptance" aspect of self-esteem. The scale was constructed with 5,024 adolescents, using the Guttman procedure, and thus the conditions of unidimensionality of scale and cumulativeness of the items underlie the scoring. The 10 items revolve around liking or disliking of self, and are answered on a 4-point Likert-type scale (strongly agree, agree, disagree, strongly disagree) which forces agreement or disagreement on each item. The 10 items are collapsed to six levels of self-acceptance, and thus each subject can receive a score ranging from 0 to 6. Low scores are associated with high self-esteem. Rosenberg (1965) achieved a Guttman scale reproducibility coefficient of .92. Test-retest coefficients (_N_ = 28) have been reported at .85 (Silber & Tippett, 1965). The same authors found the RSES to correlate from .56 to .83 with several similar measures (_N_ = 44), suggesting acceptable concurrent validity.

Death Anxiety Questionnaire (DAQ). The DAQ is a 15-item inventory of attitudes toward death and dying (Conte, Bakur-Weiner, & Plutchik, 1975). Each item is rated on a 3-point scale from 0 ("not at all") to 2 ("very much"). A high score reflects high death anxiety. Split-half reliability of scores on a heterogeneous adult sample (_N_ = 100) has been reported at .76. Internal consistency (coefficient alpha) on a separate sample (_N_ = 230) was found to measure .83. Concurrent validity coefficients were .51 and .58 when compared to the Templer Death Anxiety Scale and the Dickstein Death Concern Scales, respectively (_N_ = 40). Somewhat lower but still significant correlations with the Manifest Anxiety Scale (_r_ = .27) and an age-corrected Zung Self-Rating Depression Scale (_r_ = .40) confirm the clinical observation that death anxiety is related, though not equivalent to, anxiety and depression (Conte, Bakur-Weiner, & Plutchik, in press). This lends the DAQ sufficient construct validity for research usefulness. The scale has been demonstrated as useful with pediatric cancer patients by Koocher and colleagues (Koocher, O'Malley, Gogan, & Foster, 1980) as well as by its authors.

Experimenter Ratings

Global Assessment Scale (GAS). The GAS is a rating scale for evaluating the overall psychological functioning of a subject during a specified (one month in this study) time period (Endicott, Spitzer, Fleiss, & Cohen, 1976). The scale values range from 1 to 100. Ten anchor points are given at 10 decile intervals. The rater first selects the decile of best fit, then pinpoints the placement within that decile according to impression. Higher scores represent greater psychological health. The GAS was designed to improve upon the comparable Health Sickness Rating Scale (HSRS) of Luborsky (1962) by providing more anchor points and more behavioral descriptors, and by eliminating diagnostic constraints. It covers three major dimensions of psychopathology, impairment in daily functioning, reality testing, and potential for suicide or violence. One great advantage of this scale is the proportion of the score range which relates to non-psychiatric persons. Scores from 61 to 100 apply to people who are generally considered by those around them to be psychologically healthy. It was expected that most participants would score within this upper range.

Five studies of interrater reliability have yielded intraclass correlation coefficients from .69 to .91. Concurrent and discriminant validity are reported as adequate when the GAS is compared to the HSRS, Mental Status Examination, and to ratings by relatives (Endicott et al., 1976).

The experimenter trained himself in the rating of GAS scores by listening to taped GAS interviews of 10 breast cancer patients done at the same institution. After this, 15 interviews were rated while blind to the expert's GAS score. Interrater agreement was sufficient (_r_ = .95) to stop with confidence after 15. The GAS interview itself is unstructured, with the experimenter responsible for adequate questioning into recent disturbances of sleep, appetite, mood, psychological symptoms, self-esteem, social and work activities, interpersonal relationships, and the like.

Intimacy Motivation. This is a relatively objective, content-based scoring system applied to the story productions of six (in this study) TAT-like cards (McAdams, 1980). Intimacy motivation is defined by its author as "a recurrent preference or readiness in an individual for experiences of warm, close, and communicative exchange with others" (McAdams, 1981, p. 1). It has been demonstrated to be a more unidimensional analogue to the affiliation motive of Atkinson, Heyns, and Veroff (1954), because it emphasizes measurement of only the more positive (approach) aspects of the affiliation motive. The theoretical bases for specific categories of the intimacy motive came from the writings of H.S. Sullivan, A. Maslow, D. Bakan, and M. Buber (see McAdams, 1980). These underpinnings were integrated with the now-traditional approach of using the Thematic Apperception Test (TAT) to measure various social motives. The first such approach was by McClelland and colleagues on achievement motivation (McClelland, Atkinson, Clark, & Lowell, 1953).

The scoring system consists of 10 thematic categories which are applied to each story. At least one of two "prime" categories (relationship produces positive affect; non-instrumental dialogue) must be present for scoring to continue on that story. The eight subcategories are: psychological growth and coping gained from a relationship, commitment to or concern for another, time-space transcendence, union of characters, harmony in a relationship, surrender to outside control, escape to intimacy, and connection with the outside world. Each category receives 1 point for its presence, making 0-10 the range of possible scores per story. The scoring system as outlined in the manual is quite detailed and objective, thereby yielding high inter-rater reliability coefficients: 92% category agreement for the two "prime" categories, and Spearman rho = .89 for $N = 60$ stories (McAdams, 1980). Internal consistency has been demonstrated by principal components factor analysis which found six categories loading heavily on an intimacy factor and accounting for 30% of the total score variance. Construct validity has been supported by high correlations between Intimacy Motive Score and behavioral ratings of intimacy, $r(41) = .70$, $p < .001$ (McAdams & Powers, 1981).

The experimenter trained himself according to the instructions in the scoring manual, reviewing 210 practice stories in sets of 30, comparing scores to expert scoring along the way. On the last 60 stories, category agreement for the two prime tests was $r = .93$ for the "relationship produces positive affect" category, and $r = .90$ for the "non-instrumental dialogue" category. Rank-order agreement between experimenter and expert on the last 60 stories was rho = .92.

The six pictures used in this study depicted the following: a) two figures sitting on a park bench near a river, b) a young woman and an older man walking through a field with horses and a dog, c) a man and a woman on a trapeze, d) a ship officer speaking with another man, with a ship in the background, e) a man covering his eyes, standing near a bed with his hand outstretched over a younger man lying on a couch (TAT Card 12 M). Pictures a and c can be found in McClelland and Steele (1972). Picture d can be found in McClelland (1975).

Procedure

Assessment Session

After a patient was determined by chart review to be eligible for study, he was either telephoned or approached in person at the Memorial Hospital lymphoma clinic. Each patient was then told that the departments of hematology and psychiatry were involved in "a study of the psychological aspects of successful treatment for Hodgkin's disease," and that his participation would be appreciated. He was informed that the study was voluntary, would entail two to three hours of his time, and could be scheduled at his convenience. Upon verbal consent, an appointment was then scheduled. The location of interview and testing was either the clinic itself, the patient's home, or the experimenter's office.

All patients were seen in one session. At the outset of the session, the rationale and purpose of the study were explained briefly, and consent received (see Appendix C for consent forms). To facilitate good rapport, patients were interviewed first. After collecting basic demographic information, data for the Problem Oriented Record and the Global Assessment Scale were collected. Each patient was then given four short questionnaires: Rosenberg Self-Esteem Scale, Death Anxiety Questionnaire, Impact of Events Scale, and a measure of stressful recent life changes (Holmes & Rahe, 1967). The purpose of this fourth questionnaire was to ensure similar levels of external stress as measured by recent life changes in the five study groups. Non-significant t-tests across groups on this measure confirmed no differences in stressful life events (e.g., recent divorce, recent death in the family) across groups. Participants were allowed to fill out the above four questionnaires in any order they chose. The examiner remained present for this period with all participants.

Upon completion of the short questionnaires, each participant was given the Derogatis Sexual Functioning Inventory (which includes the Brief Symptom Inventory) and the TAT cards. These also could be filled out in any order. Instructions for the DSFI are in the test booklet. For the TAT, instructions were as follows: "Here are six pictures. I'd like you to write down an imaginative story for each picture. The story you tell is entirely up to you but it should have a beginning, middle, and end." In cases where patients were seen in the clinic, the experimenter frequently left the patient alone while he completed these more time-consuming tasks. The GAS ratings were done after termination of the assessment session. At the end of the session, patients were asked if they would be willing to ask a friend or relative of similar age to participate in the same study.

Potential non-patient subjects were contacted by telephone and asked to participate "as a member of a comparison group in a study of the psychological aspects of Hodgkin's disease and its treatment." After verbal consent, appointments were scheduled at their convenience. After obtaining written consent (see Appendix C, control form), the session proceeded in much the same fashion as with the patients. The essential differences were that the POR was shortened to include only demographic information and current rating on quality of life, and that the IES was anchored to more varied events. Specifically, eight rated their reactions to physical or medical stressors (e.g., recent separated shoulder), four rated reactions to psychosocial stressors (e.g., separation from wife), three to the death of a loved one, three to the near death of a loved one, and two to a recent career change. Because of the shortened POR, sessions with control subjects were nearly one hour shorter than with patients.

Scoring the Data

All measures except the TAT intimacy motive and the GAS rating are objectively scored and therefore resistant to possible biases from an hypothesis-wise scorer. Because the GAS interviewer and rater was the experimenter who was aware of the hypotheses of the study, this measure was conceptualized as global rating of secondary priority in the data analysis. Significance on this measure could conceivably augment other findings, but it was decided that significance on such a measure alone would hold suspicious validity. The two-tailed nature of the experimenter's thinking on cancer survival; that is, that survival from such trauma may have a positive, growthful impact on some as well as a more negative impact on others, would argue against any systematic bias in his ratings, however.

Regarding the TAT scoring, any possible bias was eliminated by a procedure which blinded the scorer to the participant's identification. All 480 stories (80 participants x 6 stories/participant) were cross-referenced by code number, then shuffled together in random fashion. Scoring of each story then proceeded with the experimenter unaware of its author.

RESULTS

This study has examined the psychological sequelae of successful treatment for Hodgkin's disease in 60 young men, by comparing them to a non-patient age-matched group of 20 men, and by exploring the effects of disease stage and time off treatment within the patient sample. The dependent measures included self-report inventories of sexual dysfunction, psychological symptomatology, coping style, self-esteem, and death anxiety, an experimenter rating of global adjustment, interview self-ratings, and a projective test measure of intimacy motivation.

The data were conceptualized in terms of a 2 X 2 factorial layout of patients (N = 15/cell) with a single comparison group (N = 20). Analysis of variance (ANOVA) was selected as the most appropriate statistical procedure. This design, a "p x q + 1," has been discussed by Winer (1971, pp. 468-473). Because it has an "unwanted" cell in the crossed layout, Winer recommends pooling the sum of squares within the comparison group with the error sum of squares and then including in the final ANOVA table a sum of squares representing the contrast between the comparison and experimental groups. Something very similar to this can be done using the SPSS "ONEWAY" procedure with planned orthogonal contrasts (Nie, Hull, Jenkins, Steinbrenner, & Bent, 1975). Even though technically the package is conducting a one-way ANOVA with five levels of one variable, the planned contrasts, if set up orthogonally, will produce independent and error variance-corrected tests for two main effects (stage and time off treatment), for the interaction of these two effects, and for a comparison of the patient group as a whole ($\underline{N} = 60$) to the comparison group ($\underline{N} = 20$). The ONEWAY design and the planned contrast values are presented in Table 3.

The presentation of analyses will be organized according to dependent measures beginning with the self-report inventories. All planned comparisons were performed through orthogonal contrast weights which assessed differences between patients and non-patients (contrast 1), the main effect of disease stage within the patient group (contrast 2), the main effect of time off treatment within the patient group (contrast 3), and the stage X time interaction (contrast 4). As suggested earlier, the independence of these contrasts from each other and the fact that they are comparisons based on a priori hypotheses eliminate the risk of increase in experiment-wise error rate due to multiple comparisons. Except in the case of the TAT ratings, where the study hypotheses were non-directional, one-tailed significance levels will be reported.

The study hypotheses follow the idea that disease (and therefore also treatment) severity and time off treatment are factors which contribute to level of measureable disturbance. Thus, the early stage-distant and the late stage-recent patients would fall on opposite ends of the continuum from low risk to high risk, respectively. For this reason, it was decided to study these two groups more closely in certain analyses, especially where the overall analysis approached significance (i.e., $.05 < \underline{p} < .10$). Because of its consistency with the study's hypotheses, this approach was considered

Table 3

SPSS ONEWAY Treatment of Data With Planned Orthogonal Contrast Values

	VARIABLE				
	Group				
	Early Recent (N=15)	Early Distant (N=15)	Late Recent (N=15)	Late Distant (N=15)	Non-Patients (N=20)
Contrast 1[1] (patient vs. non-patient)	+1	+1	+1	+1	-4
Contrast 2 (stage effect)	+1	+1	-1	-1	0
Contrast 3 (time effect)	+1	-1	+1	-1	0
Contrast 4 (stage x time)	+1	-1	-1	+1	0

[1] Because of unequal cell sizes, this contrast is not orthogonal to the others. SPSS ONEWAY makes a weighted adjustment for this.

justified on an a priori basis.

Self-Report Measures

Derogatis Sexual Functioning Inventory (DSFI). The following subtests of the DSFI were analyzed as dependent variables on the ANOVA: drive, gender role, fantasy, body image, satisfaction, global satisfaction, psychiatric symptoms (BSI - GSI), and affects balance. Although in some subtests the means fell in the order predicted, none of the differences was statistically significant (see Table 4 for means). Near significance was obtained in comparing patients to non-patients on the number of sexual fantasies acknowledged, with the patient group being lower, $F(1,75) = 3.25$, $p < .10$. Within the patient group, the difference was accounted for by the fact that the early stage patients had a more constricted sexual fantasy life than the late stage patients, $F(1,75) = 4.29$, $p < .05$. In a follow-up test between early stage patients and non-patients on the DSFI fantasy score, early stage patients were significantly lower, $t(48) = 3.37$, $p < .05$.

Brief Symptom Inventory (BSI). As with the DSFI, close examination of group mean scores on the BSI found some of them to order in a way consistent with the hypotheses (see Table 5). Most differences in means for the relevant BSI subscales were, however, also nonsignificant. One example of this is the BSI global severity index (GSI), which is the same as the psychiatric symptoms subscale of the larger DSFI (refer to Table 4). From the study hypotheses, one would expect the early-distant group (ED) to score as the least disturbed

Table 4

Mean Scores on the Derogatis Sexual Functioning Inventory Subtests for the Five Study Groups*

	Late Recent	Early Recent	Late Distant	Early Distant	Non-Patients
Drive	18.4	18.1	20.5	17.5	18.9
Gender Role	4.0	6.9	5.7	7.6	6.0
Fantasy	$7.0^{1,2}$	$5.6^{1,2}$	$8.1^{1,2}$	$5.8^{1,2}$	8.5^{1}
Body Image*	18.3	19.3	18.1	18.6	17.8
Satisfaction	7.9	7.7	6.7	8.2	7.7
Global Satisfaction	5.1	5.2	4.9	4.9	4.7
Psychiatric Symptoms (GSI)*	$.57^{3}$	$.48^{3}$	$.48^{3}$	$.41^{3}$	$.46^{3}$
Affects Balance	1.4	1.5	1.1	1.6	1.2

*High scores on the Body Image and Psychiatric Symptoms (GSI) subtests reflect high impairment. On all other subtests, lower scores reflect more disturbance.

[1] C_1: 60 patients vs. 20 non-patients, _F_(1,75) = 3.25, _p_ <.10.

[2] C_2: 30 early stage patients vs. 30 late stage patients, _F_(1,75) = 4.29, _p_ <.05.

[3] These scores are not significantly different from each other, but worth noting is that the mean of the patient scores (.49) is one full standard deviation (T score = 60) above that of the test's normative sample (_N_ = 344, _M_ = .18).

Table 5

Mean Scores on the Brief Symptom Inventory Subtests for the Five Study Groups*

	Late Recent	Late Distant	Early Recent	Early Distant	Non-Patients
Somatization	.49	.37	.39	.32	.23
Interpersonal Sensitivity	.58	.40	.58	.43	.64
Depression	.65	.46	.59	.38	.52
Phobic Anxiety	.39[1,2]	.16[1]	.09[1]	.17[1]	.17[2]
Hostility	.62	.41	.52	.48	.39
Anxiety	.59	.71	.42	.52	.54
Paranoia	.73	.68	.68	.57	.61
Psychiatric Symptoms (GSI)[3]	.57	.48	.48	.41	.46
Positive Symptom Total	20.1	18.5	16.2	16.9	18.6

*On all subtests, higher scores reflect higher impairment.

[1] C_4: Follow-up of stage X time interaction: 15 late recent patients vs. 45 other patients, $t(58) = 2.41$, $p < .01$.

[2] Fifteen late recent patients vs. 20 non-patients, $t(33) = 1.46$, $p = .077$.

[3] See Table 4, footnote 3, for explanation.

and the late-recent group (LR) to score as the most disturbed of the patient groups, with the other two patient groups (ER & LD) in between. The non-patients (NP) would be expected to score slightly better than the ED group. On the GSI, $M_{LR} = .57$, $M_{ER} = .48$, $M_{LD} = .48$, $M_{ED} = .41$, and $M_{NP} = .46$. It is worth noting that these patient scores on the GSI ($M_{patient} = .49$) fall one full standard deviation above the mean of the BSI's normative sample of 344 male non-patients ($M_{age} = 46$, $SD = 15$)(Derogatis & Spencer, 1982). This is one standard deviation in the direction of higher disturbance than the principal normative sample of the BSI. It is, however, also nearly one standard deviation below the mean GSI score of 425 male psychiatric outpatients ($M_{age} = 31$, $SD = 12$).

A trend toward significant lowering of phobic anxiety as measured on the BSI was detected when comparing patients recently completing treatment to those distantly off treatment, $F(1,75) = 2.92$, $p < .10$. A test of the significant stage X time interaction (C_4) showed the difference to be largely attributable to the very high score for the late-recent group ($M = .39$) as compared to the other patient groups combined ($M = .14$), $t(58) = 2.41$, $p < .01$. This late-recent group mean score (.39) was not significantly higher than the control group score ($M = .17$), but there did appear to be a trend toward this, $t(33) = 1.46$, $p = .077$ (see Table 5).

Impact of Events Scale (IES). The IES yields two separate scores: intrusive thinking and avoidant thinking, which can be combined to a total score. Among the planned contrasts, a difference between patients and non-patients on avoidant thinking was confirmed (see Table 6). In following up that difference, the Least Significant Difference procedure (LSD) was applied to the range of scores across the groups for avoidant thinking, and the early-recent group mean was significantly greater than the non-patient group mean ($p < .05$). In keeping with the earlier identification of a probable "low risk group" (ED) and a probable "high risk group" (LR), the same LSD test was applied to the intrusive thinking scale, with attention paid only to the comparisons of these two groups' means. The difference was significant ($p < .05$), suggesting that there may be some additive effect of stage and time off treatment in influencing coping style and intrusive thinking. See Table 6 for mean scores and relevant comparisons.

When contrasts were set up to compare the early-distant group to the other patients, excluding non-patients, they were found to be significantly more well-adjusted than the other groups combined with regard to intrusive thinking, $t(58) = 2.28$, $p < .05$, and with regard to the overall IES score, $t(58) = 1.89$, $p < .05$, but not with regard to the avoidant thinking score.

Rosenberg Self-Esteem Scale (RSES). This is a 10-item scale which measures the self-acceptance aspect of self-esteem. Lower scores reflect higher self-esteem. There were no significant differences between groups in any of the four planned contrasts. One difference between means which neared significance involved the early stage group's tendency to score higher on self-esteem ($M = .80$) than the late stage group ($M = 1.37$), $F(1,75) = 2.47$, $p < .10$.

Table 6

Impact of Events Scale: Mean Comparisons

	Patient Groups				Non-Patients
	Late Recent	Late Distant	Early Recent	Early Distant	
Intrusive Thinking**	8.47^b	7.53	7.27	3.07^b	5.00
Avoidant Thinking*	7.47	8.07	11.00^a	6.00	4.32^a
Total**	15.94	15.60	18.27	9.07	9.32

*C1: Patients scored significantly higher than non-patients, *F*(1,74) = 5.61, $p < .05$.

**Early Distant (low risk) group significantly lower than other patient groups combined.

[a] Least Significant Difference (LSD), significant at $p < .05$.

[b] LSD significant at $p < .05$.

Death Anxiety Questionnaire (DAQ). This is a 15-item scale of attitudes toward death and dying. Higher scores reflect higher death anxiety. As was the case with much of the DSFI and BSI, the order of means (especially for the time off treatment effect) is in the direction predicted. However, no planned comparisons yielded significant differences on the DAQ. Within the patient group, $M_{\text{recently off treatment}} = 8.44$, and $M_{\text{distantly off treatment}} = 7.43$.

To summarize this section, planned statistical analyses of the self-report data provided minimal support for the study hypotheses. While the ordering of means across groups often was in the predicted direction, rarely did the differences reach significance. Follow-up statistical handling of these non-significant-but-predicted ordering of means for all dependent measures will be described at the end of this chapter.

Confirmed hypotheses were the following: Early stage patients demonstrated more constricted sexual fantasies than non-patients on the DSFI. Patients in general also tended to use a more avoidant thinking style than non-patients in reference to a past traumatic event. While patients did not differ from this study's comparison group on psychiatric symptomatology, they did score an average one standard deviation above the DSFI normative male sample. Within the patient group, late stage patients recently off treatment had significantly higher phobic anxiety than the other patient groups combined. They also showed more intrusive thinking about their cancer than the early-distant patient group. The low-risk, early-distant group did appear to be more well-adjusted than the other three patient groups on the Impact of Events Scale (intrusion and total scores both lower).

Experimenter Rating: Global Assessment Scale (GAS)

Like the self-report measures, the GAS data were analyzed via the ANOVA with four planned contrasts. The GAS is a global rating, between 1 and 100, of overall psychological health and adjustment, based primarily upon recent symptomatology.

The order of means on the GAS, from lowest to highest score, was as follows: $M_{LR} = 70.0$, $M_{ER} = 74.9$, $M_{LD} = 75.7$, $M_{ED} = 77.5$, $M_{NP} = 78.4$. This is the predicted order, but again the differences between means only approached significance. For the patient to non-patient comparison (Cl), $F(1,75) = 1.88$ (NS); and for the recent to distant time off treatment comparison (C3), $F(1,75) = 2.16$ (NS). The difference between means of the low risk (ED) versus the high risk (LR) groups was statistically significantly; however, $t(28) = 1.88$, $p < .05$. the high risk (LR) patients also had significantly lower GAS scores than the non-patient group, $t(33) = 2.02$, $p < .05$.

The GAS data, while they do not directly confirm the study hypotheses, do provide further illumination. The ordering of means and pursuant significance testing lends further support to the identification of low risk (ED) and high risk (LR) patient groups.

Projective Testing: TAT Intimacy Motivation

All statistical handling of intimacy motivation involved two-tailed probability distributions for significance testing. This was because of the open-ended nature of the study hypotheses for this measure due to the contradiction in the existing literature.

As seen in Table 7, patients' intimacy motivation as scored on the TAT was significantly lower than that of the non-patient group, $F(1,75) = 5.34$, $p < .05$. The absence of other significant within-patient comparisons suggests that this lowered intimacy motivation is a patient-wide phenomenon which is not necessarily exacerbated by severity of disease or ameliorated by time. A closer look at each story across the five groups was done to help determine if any could be found to be more discriminating than the others. Indeed, it appears that the third picture (trapeze), while it yielded low scores in all groups, did discriminate patients from non-patients in a way similar to the total (six story) score, $t(78) = 2.36$, $p < .05$. The open field scene scores also yielded a higher patient to non-patient difference, but the difference did not reach statistical significance. Table 8 presents the mean intimacy motivation scores for all patients compared to non-patients for each story.

In summary thus far, support for the polarization of early stage patients distantly off treatment and late stage patients recently off treatment into low and high risk groups, respectively, has been provided by the BSI phobic anxiety subscale, the IES and the GAS. In addition, the projective measure of intimacy motivation has revealed an apparent reduction in need for intimacy in the cancer sample in general.

Interview Data: Revised Problem Oriented Record (POR)

Most of the POR was not intended for use as a dependent measure for hypothesis testing (see Appendix A). Its chief purposes were to

Table 7

Planned Comparisons of Mean

TAT Intimacy Motivation Scores (N = six stories)

		Disease Stage			Non-Patients
		Early	Late	M_{time}	
Time Off Treatment	Recent	$M=3.73$ ($N=15$)	$M=5.47$ ($N=15$)	$M=4.60^{c}$ ($N=30$)	$M=6.15^{a}$ ($N=20$)
	Distant	$M=3.20$ ($N=15$)	$M=4.53$ ($N=15$)	$M=3.87^{c}$ ($N=30$)	
	M_{stage}	$M=3.47^{b}$ ($N=30$)	$M=5.00^{b}$ ($N=30$)	$M_{tot}=4.23^{a}$ ($N=60$)	

[a] C1: patients to non-patients, $F(1,75) = 5.34$, $p < .05$

[b] C2: early to late stage patients, $F(1,75) = 3.42$, $p < .10$

[c] C3: recent to distant time off treatment, F = NS

C4: stage x time interaction, F = NS

Table 8

Patient to Non-Patient Comparisons on Mean Intimacy Motivation Scores by Story

Story	Mean Patient Score	Mean Non-Patient Score	$M_{np}-M_{pt}$	t value
1. River Scene	1.83	2.15	.32	NS
2. Open Field Scene	.95	1.70	.75	1.84*
3. Trapeze	.22	.85	.63	2.36**
4. Ship Captain	.18	.20	.02	NS
5. TAT 13MF	.63	.90	.27	NS
6. TAT 12M	.42	.35	-.07	NS
TOTAL	4.23	6.15	1.92	2.31**

*$p < .10$

**$p < .05$

aid in systematic collection of demographic and patient treatment information, to gather patients' retrospective accounts and ratings of their treatment experiences which might prove to be useful in identifying key treatment issues vis-a-vis adaptation to illness, and to establish problem incidence rates in the post-treatment period with the four treatment groups collapsed into one group of 60 (see Appendix A). That is, most of the questions asked in the POR were not expected to show meaningful differences between patient groups. They were intended for the most part as frequency tabulations of target problems.

There were, however, 16 items on or added to the POR which were designated as testable, with predicted outcomes. These will now be summarized under three categories: Quality of life ratings, pre- and post-treatment self-ratings, and conditioned symptoms (including survival concerns). After this summary of planned comparisons is presented, qualitative and quantitative summaries of patient responses to selected interview questions, with statistical handling of differences when appropriate, will be given.

Quality of life ratings. Unlike other categories, the quality of life category consists of patient-to-non-patient comparisons as well as patient-to-patient comparisons. In order to accomplish this, non-patient participants were asked the same questions, controlling for time by having 10 of them discuss their response to a stressful event six months to two years ago ($\underline{M}$ = 13.4 months), and 10 to an event three to seven years ago ($\underline{M}$ = 67.3 months).

It was found that non-patients, on the average, were working

2.5 hours per week more than they had been prior to their "stressful event." The patient sample, on the other hand, was working 5.7 hours less per week than before diagnosis. This difference was significant, $t(68) = 1.77$, $p <.05$, and the bulk of this drop in patient return to work was accounted for by the "high risk" late-recent group. They were, on the average, still working 12.5 hours less than their pre-illness levels. The difference was significantly different ($p <.05$) from non-patients, using the least significant difference test (see Table 9). There were no significant differences across groups in the participants' interview ratings of sexual or marital satisfaction.

The other quality of life indicators designated for study were three ratings of life appreciation and overall satisfaction. On the first question, significantly more patients (85%) than non-patients (55%) acknowledged an increase in life appreciation, $\chi^2(1) = 7.74$, $p <.01$. There were no differences within the patient group on this rating, however, though the means did order in the predicted direction for time off treatment. This heightened sense of life appreciation in the patient sample is further supported by the second rating, a 1 to 10 scaling of "how much more" each participant appreciated life. Mean ratings by patients ($M = 6.13$) and non-patients ($M = 3.25$) also differed significantly, $F(1,75) = 11.56$, $p <.001$. The third rating is the POR "Life Scale" rating. This asks each participant to compare the overall quality of his current life on a "-10" to "+10" scale, with 0 as the "no change" point, to that before his illness ("two" or "six" years ago in the case of non-patients). Patients did not differ from non-patients on this measure, nor did early and late stage patients differ from each other. However, the patients recently off treatment had lower ratings than those distantly off treatment (_M_= 2.3 versus 4.7, respectively), _F_(1,75) = 4.80, $p < .05$. The life scale ratings of this group recently off treatment were also lower than non-patients (_M_= 4.6), _t_(48) = 1.84, $p < .05$.

Pre- and post-treatment self-ratings. These four ratings apply to patients only. They include the patients' subjective sense of current physical stamina, sleep patterns, eating habits, and concentration ability (depressive equivalents) as compared to their recall of pre-illness functioning (Table 9). In all cases, disturbance was expected to be higher in the late stage and recent treatment groups. Overall, 57% of the patient groups (34 of 60) believed that they had not yet regained premorbid levels of physical stamina, 27% of them (16 of 60) felt that they were sleeping worse than before their illness, 13% (8 of 60) thought they were eating worse, and 27% (16 of 60) believed they had lost some concentration ability in the time that had elapsed. This compares to 5% (3 of 60) who felt they were in better physical shape now, 10% (6 of 60) who stated they were sleeping better, 21% (13 of 60) who said they were eating better, and 17% (10 of 60) who acknowledged better concentration. Neither disease stage nor time off treatment was a discriminating variable for these ratings. Because of the non-significance of the main effects, data were collapsed across groups to highlight prevalence rates of these four problems (see Table 9).

Conditioned symptoms and survival concerns. This section also refers to patients only. Therefore, a more focused 2 X 2 ANOVA was

Table 9

Qualify of Life Ratings (N=80) and Patient

Self-Ratings of Depressive Equivalents (N=60)

QUALITY OF LIFE RATINGS	Non-Patients (N=20)	Patients (N=60)		
Return to Work (pre-post hr/week difference)	+2.5	-5.7 (-12.5 for LR's)		$t(68)=1.77, p<.05$ LSD**, $p<.05$
Life Appreciation --percent acknowledging increase	55%	85%		$\chi^2(1)=7.74, p<.01$
--1 to 10 rating of increase	M=3.25	M=6.13		$F(1,75)=11.56$, $p<.001$
Life Scale Rating (-10 to +10)	(N=20)	Recent (N=30)	Distant (N=30)	1. Recent vs. Distant
	M=4.6	M=2.3	M=4.7	$F(1,75)=4.8$, $p<.05$ 2. Recent vs. Non-Pt's, $t(48)=1.84$, $p<.05$

PATIENT PRE-POST RATINGS OF DEPRESSIVE EQUIVALENTS (N=60)

Physical Stamina*	worse	57%
	better	5%
Sleep Patterns*	worse	27%
	better	10%
Eating Habits*	worse	13%
	better	21%
Concentration Ability*	worse	27%
	better	17%

*Disease stage and time off treatment did not differentiate patients on any of these variables.

**LSD = Least Significant Difference

performed on these particular data. This was done in order to provide an analysis with a more appropriate error term by eliminating the unused non-patient group. Each patient was asked about the presence (scored 1) or absence (scored 0) of nausea or related gastrointestinal symptoms to the three conditioned stimuli: various smells (e.g., rubbing alcohol, cleaning fluids), being in the treatment clinic, and "anything else" (e.g., certain foods, songs, colors, people). Thus, each patient received a score ranging from 0 ("no conditioning") to 3 ("conditioning in at least three areas") for symptoms of nausea. The same inquiry and scoring criteria were applied to actual vomiting; and to anxiety, defined as "feeling of nervousness, or being upset emotionally but not necessarily physically." There had to have been an incident within the past five months for any symptom to be scored. The three scores were also combined to yield a total conditioning score for each patient. Table 10 presents the summary tables of the treatment-related conditioning data. As the table suggests, there does appear to be a significant lessening of conditioned symptoms over time. The total conditioning score was higher in the later stage patients ($p < .05$). Closer examination of the contributions to this total conditioning score revealed quite clearly that the stage and time effects are almost completely accounted for by the nausea score, where both later stage patients and those recently off treatment show significantly greater disturbance. Actual vomiting was expectably rare (4 of 60 patients) and therefore non-significant across patient variables. The fact that conditioned anxiety does not appear to drop off significantly over time and is no less a problem in the early

Table 10

Analysis of Variance Summary Tables for Patient Conditioning Scores

Dependent Variable	Source	df	Mean Square	F Ratio
Total Conditioning Score	Main Effects			
	--stage	1	9.60	3.32+
	--time	1	13.07	4.52*
	Interaction			
	--stage x time	1	.07	.02
	Residual	56	2.89	
Nausea Score	Main Effects			
	--stage	1	3.27	4.27*
	--time	1	3.27	4.27*
	Interaction			
	--stage x time	1	.27	.35
	Residual	56	.77	
Vomit Score	Main Effects			
	--stage	1	.07	1.04
	--time	1	.07	1.04
	Interaction			
	--stage x time	1	.00	.00
	Residual	56	.06	
Anxiety Score	Main Effects			
	--stage	1	1.07	.89
	--time	1	2.40	2.00
	Interaction			
	--stage x time	1	.07	.06
	Residual	56	1.20	

$^{+}p < .10$

$^{*}p < .05$

stage patients of this sample runs counter to the study hypothesis, and will be discussed in the following chapter.

The final three planned comparisons from the POR relate to patients' concerns with survival as reflected in: 1) their rating of how fearful they are of recurrence (1-10 scale); 2) the presence of heightened attention to one's body (e.g., checking for enlarged nodes while in the shower); and 3) somatic anxiety, defined as "becoming upset over little aches and pains which never would have bothered you before." The mean fear of relapse rating, where 1 = "not at all," and 10 = "extremely so," was 4.92. A two (stage) by two (time) ANOVA revealed no significant differences among patient groups. Regarding the presence of heightened health awareness (which most patients reported was not coupled with anxiety), 85% of 60 patients acknowledged that their awareness of their health and concern for symptoms had increased because of their having had cancer. The difference between early and late stage patients (with more late stage patients being attentive) approached significance, $\chi^2(1) = 3.40$, $\underline{p} < .10$. Of 60 patients, 63% reported some degree of somatic anxiety when day-to-day functioning was disrupted by minor aches and pains. This was especially true when no explanation could be found for a new-found pain or ache. Disease stage and time off treatment were not discriminating factors in the chi-square analyses of these data.

A review of the planned comparisons on interview data revealed generally solid support for the following: 1) late stage patients recently off treatment had the greatest difficulty with work adjustment as measured by return to premorbid number of work hours; 2) all patients, especially those off treatment for longer periods of time, show a heightened appreciation for life. However, the patients recently off treatment rated their current life with significantly less improvement than both the non-patients and the patients distantly off treatment; 3) all patients, regardless of stage or time off treatment, demonstrated high frequencies (greater than 25%) in three out of four of the "depressive equivalents" surveyed in the interview; 4) conditioned nausea appears to be worse for later stage patients (as predicted), and tends to diminish over time (as predicted); 5) conditioned anxiety does not appear to have the same predictability (and is therefore perhaps more a trait measure); and 6) disease stage and time off treatment did not discriminate patients on ratings of recurrence fear, somatic self-awareness, and somatic anxiety (again suggesting a possible trait factor).

Following is a summary of problem areas identified by the POR interview which were not built into the study hypotheses. The summary will be divided into three parts: Retrospective treatment ratings, ratings of treatment and post-treatment difficulties, and patient fertility data. While not directly relevant to the study hypotheses, these data are added here because they indirectly bear upon questions under investigation in that they provide further information about the concerns and experiences of patients off treatment.

Retrospective treatment ratings. Patients were asked many questions about their reactions to diagnosis and treatment. For example, they were asked to rate, on a 1 to 10 scale, the intensity of their reaction to their disease symptoms before they knew of their diagnosis (_M_ = 3.12, _SD_ = 2.9). This can be compared, for instance, to their reaction to being told the diagnosis of Hodgkin's Disease (_M_ = 6.25, _SD_ = 3.0), suggesting something akin to a doubling of distress when the signalling of illness becomes identified as a life threat. A similar comparison emerges from patients' retrospective ratings of their view on the seriousness of their illness (1 = "nothing at all," 10 = "life and death" illness) at various points along their treatment. Means order downward from the point of diagnosis (_M_ = 6.73), to the treatment period (_M_ = 5.12), and finally into the present (_M_ = 2.20).

Of the three treatment modalities used (surgery is included here) the patients' rating of emotional reaction to chemotherapy appears to be the most highly distressed (_M_ = 6.0), with radiation and surgery remembered as somewhat less distressing (_M_ = 4.3 and 4.2, respectively).

Ratings of treatment and post-treatment difficulties. Tables 11 and 12 are summary tables which present the percentage of patients who acknowledged the presence of various difficulties during treatment and in the post-treatment period. In reference to Table 11, informal comparison of the change in percentages, from the treatment period to the post-treatment period, suggests there is a drop in social irritability, depressed mood, sleep disturbance, concentration difficulty, marital discord and sexual dysfunction after treatment ends. The drops in sleep disturbance and concentration difficulty are less dramatic than the others. Also, in light of the low base-rates

Table 11

Patient Frequencies of Symptoms and Psychosocial Difficulties Acknowledged In- vs. Off-Treatment

SYMPTOMS	In-Treatment	Off-Treatment	Chi Square
Irritability	68%	35%	$\chi^2(1)=13.36$***
Depressed Mood	83%	62%	$\chi^2(1)= 7.06$**
Sleep Disturbance	50%	27%	$\chi^2(1)= 6.90$**
Concentration Difficulty	47%	27%	$\chi^2(1)= 5.18$*
Suicidal Ideation	7%	10%	<u>NS</u>
Contact with Mental Health	17%	18%	<u>NS</u>
Psychotropic Medication	22%	13%	<u>NS</u>
PSYCHOSOCIAL DIFFICULTIES			
Change in Relationship with Significant Other	worse=45% better=18%	worse=22% better=35%	$\chi^2(2)= 8.36$*
Change in Sexual Functioning	worse=62% better=7%	worse=18% better=44%	$\chi^2(2)=30.60$***

*$p < .05$

**$p < .01$

***$p < .001$

Table 12

Patient Frequencies of Post-Treatment Difficulties in Somatic, Psychosocial, and Occupational Areas*

SOMATIC/PSYCHOSOCIAL	Post-Treatment
Symptom Distress	67%
Physical Discomfort	48%
Sexual Difficulties	18%
Sexual Dissatisfaction	55%
Negative Post-Treatment Reaction by s/o**	30% (13 of 43)
Family Problems	38%
Change in Family Relationship(s)	worse = 13% better = 23%
Friend Problems	30%
Change in Friend Relationships	worse = 13% better = 25%
OCCUPATIONAL	
Occupational Choice Influenced by Illness	worse = 27% better = 5%
Still in Debt	42%
Employer Treats Differently Because of Illness	14% (6 of 43)
Co-Workers Treat Differently Because of Illness	22% (11 of 50)
Out of Work Due to Illness	2% (1 patient)

*Except where indicated, all patient percentages are based upon an N of 60 patients.

**s/o = Significant Other

suggested by the non-patient responses to these two areas (10% complained of sleep disturbance and 5% complained of concentration difficulty), there is some indication that sleep and concentration difficulties tend more often to continue to plague the surviving Hodgkin's patient over time. These conclusions are impressionistic, based only on frequency tabulations and unplanned post hoc comparisons.

Table 12 presents only post-treatment ratings. Two out of every three patients have acknowledged physical symptoms which have been distressing to them because they bring on a fear of recurrence ("symptom distress" item). These symptoms were typically stiff neck, swollen glands, common flu or cold symptoms, or fatigue. One may note the similarity of these symptoms to the B symptoms of Hodgkin's disease. Nearly half (48%) of them have complained of some physical discomfort, which many of them attributed to lingering chemotherapy or radiation effects. Nearly one in five, as compared to none of the non-patient sample, have acknowledged significant post-treatment sexual readjustment difficulty, but most felt they had overcome this by the time of the interview. Neither disease stage nor time off treatment were associated with varying frequencies in these areas. The 55% frequency of sexual dissatisfaction in the patient sample (see Table 12) is compared to a figure of 65% in the non-patient sample. Thus, this high figure is probably more a function of the suggestive nature of the question than of any unusually high prevalence of sexual dysfunction.

As Table 12 illustrates, psychosocial problems with family and friends were not numerous. What is more, many of those patients who experienced them felt they had overcome their difficulties by the time of the interview. What was more striking was the fact that one-fourth of the sample felt that the experience of cancer had brought them closer to certain friends and family members. As one patient put it: "It forced me to set my priorities in people. . . to see who I really cared about and tell them." Such relationships were commonly seen in the post-treatment period as much more solid because of the heightened intensity of the relationship during the treatment period.

Regarding the occupational area, three patients changed careers in a positive way because of their illness. One, for example, took up nuclear medical technology because he was so fascinated by the radiation treatment process. However, 27% of the men felt that their careers had suffered in some unmeasurable (often unprovable) way. Most such men would comment on the fact that they have avoided career risks in favor of the security (i.e., insurance benefits) which their pre-morbid job provided. Many were still in debt for incurred medical expenses. Very few people felt their employers or co-workers treated them overtly differently because of their illness. Of those who did, the "different" treatment was usually in a more favorable direction (e.g., not making him work as hard, being more understanding about days off, etc.). In conclusion, then, very few complained of overt discrimination or occupational mistreatment, but a substantial number lamented what they perceived as missed career opportunity because of their own felt need to retain job security.

Patient fertility data. This section will close with a brief summary of the data collected on patient fertility. As indicated by the fact that 62% of the patients interviewed would like to have children, and by the patients' frequent admission of distress in this area, the issue of compromised fertility in young men treated for Hodgkin's disease is a critical one. This study's finding that 90% (20) of the 22 patients who had recent sperm counts remain sterile is in agreement with the sterility figures of the Redman study (Redman, 1983) and others. The 38 patients who had not been tested for fertility were asked their current belief on their own status (see Table 13). A great proportion of them (61%) believed that they had either regained or had never lost fertility. It is unclear whether this is due to patient optimism, lack of information, or the result of a doctor-patient relationship in which patients are encouraged to think positively. The level of distress measure in Table 13 refers to the entire sample of patients, giving their rating (1-10) of how upsetting their sterility is to them as well as to their significant other (when the patient had a significant other). The scores presented are underestimates in that there were some patients who were extremely upset by this (e.g., six "10" scores).

Conclusion

The self-report measures, particularly the Impact of Events Scale, the BSI Phobic Anxiety subscale, and the DSFI Fantasy subscale, provided a small degree of support for the study hypotheses, and somewhat more evidence for a justified grouping of high risk (late-

Table 13

Patient Fertility Data

Number of Patients Who Want Children in the Future		62% (37 of 60)
Sperm Count Data:	Patients Tested as Fertile	3% (2 of 60)
	Patients Tested as Sterile	33% (20 of 60)
	Patients Not Tested	64% (38 of 60)
Untested Patients' Belief in Their Fertility:		
	Believe Fertile (actual probability = .10)	61% (23 of 38)
	Believe Sterile (actual probability = .90)	34% (13 of 38)
	Won't Say	5% (2 of 38)
Mean Sterility Distress Rating (1-10 Scale)		
	Patients	2.8
	Patients' Rating of Significant Other	2.7

recent) and low risk (early-distant) patients. This was corroborated by the Global Assessment Scale. Projective testing and interview responses, on the other hand, have given much stronger support for the following conclusions about Hodgkin's disease patients in general: 1) lowered capacity for intimacy in personal relationships; 2) heightened life appreciation which increases over time; 3) high incidence of symptoms which are possible depressive equivalents; 4) a trend toward lessening of these and other symptoms and difficulties over time; 5) significant post-treatment conditioned nausea which abates over time; and 6) significant post-treatment conditioned anxiety which does not lessen significantly over time.

It was asserted at many points in this chapter that the mean differences on various dependent measures, while not significant, were aligned in the predicted order. Because it seemed that the predicted ordering of means occurred more often than expected by chance, a post hoc analysis of the data was performed. Essentially, this entailed calculation of a $\underline{z}$ score based upon the binomial probability of achieving significantly more predicted mean-orders than attributable to chance. This analysis was done for all hypotheses which applied to patients <u>and</u> non-patients. TAT data were not included because their hypotheses were not unidirectional.

A binomial $\underline{z}$ (Siegel, 1956) was calculated for both independent variables, disease stage and time off treatment. Each variable had three levels: early (E), late (L), and non-patient (NP) for stage; and recent (R), distant (D), and non-patient (NP) for time off treatment. There were 25 comparisons with unidirectional hypotheses which included non-patients: Four in the interview, 15 on the DSFI (including the BSI), three on the IES, and one each for the DAQ, RSES, and GAS.

For the disease stage variables, eight of the 25 sets of mean orders were in the predicted direction. Chance probability would be one in six, so

$$\underline{z} = \frac{8 - 1/6(25)}{\sqrt{25 \times 1/6 \times 5/6}} = 2.06(\underline{p} < .05).$$

For the time off treatment variable, 10 of the 25 sets of mean orders were in the predicted direction, so

$$\underline{z} = \frac{10 - 1/6(25)}{\sqrt{25 \times 1/6 \times 5/6}} = 3.13(\underline{p} < .05).$$

Thus, the trends noted throughout this chapter receive some secondary statistical support. While differences between means, even when correctly ordered, rarely showed significance (except in the interview material), the fact that the means arrange in the predicted order far greater than chance expectation lends credence to the notion that the impact of cancer and its treatment upon the individual, while often subtle, is apparent and demonstrable.

DISCUSSION

The present study has provided a comprehensive overview of adaptation to survival from cancer. Globally, the results of this study are heartening in that very little severe psychopathology in the patient sample was uncovered by the self-report measures, experimenter ratings, or interview data. In fact, the majority of patients acknowledged a heightened sense of life appreciation and purpose as a result of the cancer experience. However, one must also note the significant adaptational difficulties and moderate disruptions identified by this study which balance if not outweigh the growthful component of the experience.

The findings of this study agree only in part with three disparate conclusions about cancer survival gleaned from the literature: 1) that cancer survival is associated with heightened psychosocial and psychosexual dysfunction (e.g., Holland, 1981, 1982b; Koocher & O'Malley, 1981); 2) that cancer survival is associated with greater life appreciation and character growth (e.g., Kennedy et al., 1976); and 3) that cancer survival is not associated with significant change in either a positive or negative direction (e.g., Craig, Comstock, & Geiser, 1974; Holmes & Holmes, 1975; Li & Stone, 1976). As the bulk of the literature review had suggested, there appears to be some amount of truth in each of these assertions. At the same time, however, these assertions cannot be offered without exceptions and qualifications.

The severity of disease at the time of diagnosis and the amount of time elapsed since the termination of treatment both showed themselves to be important factors in selected areas of psychological functioning and basic well-being. This was demonstrated most convincingly when these two factors were combined to create, out of four patient groups, a "low risk" group (early stage at diagnosis-distantly off treatment) and a "high risk" group (late stage at diagnosis-recently off treatment). That is, there was substantial evidence for high risk patients showing more adaptational difficulty than low-risk patients.

This discussion will elaborate upon these general conclusions, and speculate about the adaptational challenges of Hodgkin's disease survival. To accomplish this, the study results will be presented in two sections: differences between patients and non-patients, and differences within the patient group across independent variables of disease stage and time off treatment, including the prevalence of problems within the patient group in general.

Differences Between Patients and Non-Patients

Of 25 planned comparisons between patients (*N* = 60) and non-patients (*N* = 20), five produced statistically significant results. Many of these comparisons were made possible by the anchoring of non-patient responses to past stressful events in their own lives. Two of these five significant results were "positive" findings: that more patients displayed a heightened appreciation for life in the post-treatment period when compared to non-patient self-ratings, and that the extent of increased appreciation for life was significantly greater in the patient sample. These findings are consistent with those of Kennedy and colleagues (1976) as well as Shanfield (1980). This suggests that the cancer experience acts as a catalyst to mobilize awareness of one's mortality and subsequent improved attitude toward life. The presence of heightened life appreciation in the successfully treated cancer patient is not one which is greatly contested in the literature. The more controversial issues are with regard to the presence or absence of other, more disruptive consequences which can significantly hamper the quality of the survivor's post-treatment life.

To the extent that quality of life can be measured by return to pre-morbid work functioning, there would appear to be significant disruption. Patients (especially late stage recently off treatment) showed far greater difficulty returning to work after treatment than non-patients did after comparison trauma. Granted, the stressors for the non-patient group, such as divorce, physical injury, or death of a loved one, do not match the intensity of the stress of diagnosis and treatment of cancer. However, in defense of the conclusion of hampered return to premorbid work level in cancer patients, one goal of this study is in fact to establish that these stressors (diagnosis and treatment) constitute something more intense than the non-patient group's various stressors. Further support was lent to the conclusion that post-treatment work functioning suffers by the observation that 27% of the patient sample admitted to choosing job security over potential career advancement because of the insurance and employment risks involved in career change.

Another major finding was that patients demonstrated significantly more avoidant thinking on the Impact of Events Scale. Again, this is tempered by the fact that patients and non-patients had anchored their responses to very different stressful past events: Patients to their cancer diagnosis and non-patients to a variety of physical and psychosocial events. It was the intention of this study to investigate the notion that the stress of diagnosis and treatment of Hodgkin's disease continues through the survival period to inflict demonstrable demands upon the person's adaptational capabilities. Thus, when patients off treatment for one (and even five) years use more avoidant thinking with regard to their illness than non-patients do with regard to other (albeit milder) past stressors, it is safe to say that the patients in this sample still show a strong tendency to defend themselves against the potential disruption which could result from thinking about their treatment experiences. While true of all patients, this was most true of those recently completing treatment, suggesting a tapering, though not elimination, of avoidant thinking over time. Intrusive thinking seems to taper more quickly, as demonstrated by the high intrusion subtest score for late stage-recent patients as opposed to very low scores in the early stage-distant group.

While avoidant thinking is not strictly the same as denial, the observation that patients in general tend to use avoidant thinking is consistent with previous reports of denial as a principal coping mechanism in cancer adaptation (e.g., Hackett & Weisman, 1969; O'Malley et al., 1979). It would also appear that the hypothesized lifting of denial in the service of integration as the survival period extends received little support in that patients distantly off treatment tended to be less avoidant but less intrusive than those recently off treatment. The early stage patients distantly off treatment had significantly less intrusive breakthrough than the late-recent group in particular and all patients in general. This suggests that the group distantly off treatment does not show more psychiatric symptomatology, however, as might have been predicted by Derogatis, Abeloff, and Melisaiatos (1979), or by Rogentine and others (1978). The formulation of Koocher and O'Malley (1981) and Weisman and Worden (1976-77) seem to fit this study's data better. They would suggest that denial is important in the beginning stages of cancer diagnosis and treatment, and that it gradually lifts, while the patient paces his integration of the experience according to his capability. Actually, optimal denial might be better termed "suppression," as it involves the capacity to identify distress yet minimize it through activity and gradual integration. Vaillant (1976), in his discussion of the dynamic development of character and defense structure, has also identified this defense of suppression as particularly adaptive and healthy in the face of stress, as it combines awareness of difficulty and conflict with stoicism and mastery.

Another significant difference between patients and non-patients, and what is considered to be a major finding of this investigation, was that patients were found to have lowered intimacy motivation, as measured by their projective story-telling. There were no differences within the patient group, suggesting this is a patient-wide decrease. This result was also corroborated by informal comparison of patient mean scores to normative sample mean scores on those pictures (river, field, trapeze, ship) which had normative data available (McAdams, 1981).

In its broadest sense, this result would suggest that a constriction of one's availability for warm interpersonal exchange is part of the lingering aftermath of successful cancer treatment in young men. A speculative explanation for this could be that the cancer experience sets these young men apart from their peers and age-mates, and that this sense of separateness can have a socially isolating effect. In the interview, many patients stated that the ordeal of cancer and their struggle to conquer it gave them a feeling of superiority over others. They felt special, at times even "chosen" to live on. One patient in his mid 30's likened the ordeal to his Viet Nam experience. He felt embroiled in battle with his disease, and developed special, very close relationships with his treatment staff. However, just like a soldier returning from war, he realized upon re-entry to "normalcy" that he had been changed by the experience, and he did not seem to fit in. He came to feel that anybody who was not with him during the treatment could never really understand its impact. It is conceivable, then, that this displaced but special feeling may contribute to difficulty engaging in satisfying interpersonal relationships, especially in young men who do not go through treatment with a significant other close at hand.

Another possible explanation for lowered intimacy motivation in the patients could relate to apprehension and uncertainty in the face of disruptions of their role functioning. As suggested by Kennedy and others (1976), Leiber and others (1976), and Sutcliffe (1979), and referring to Erikson's (1950) general comments about young adulthood in men, the impact of cancer and treatment upon a young man's role functioning may indeed show itself through interpersonal constriction. These investigators would agree that the dependency and passivity induced by cancer treatment constitute an impetus for counterdependent maneuvers in the service of denial of need and reinforcement of masculine role functioning. It would make sense, then, that these men would tend to constrict their motivation toward interpersonal warmth and closeness, as a protection against the threat of the passive patient role. Why, then, would so many of them say that their relationships with their wives has improved (35%), or that they feel genuinely closer with their extended family (23%), since treatment ended? It may be that some men, especially those who begin the treatment ordeal with strong object ties, actually experience enhancement of their interpersonal lives without threat to their role-related self-esteem. This would be consistent with Weisman's (1975) finding that satisfying and constructive interpersonal relationships during and after treatment were associated with longer survival time. On the other hand, those who are either single or unhappily married might experience drops in intimacy capacity of a proportion great enough to lower the grand mean of all 60 patients on intimacy motivation. The fact that 22% of patients believed that their relationship with their significant others had worsened since treatment ended, and that 38% experienced "family problems," might indirectly support this formulation. As one patient's wife said to the investigator upon completion of the patient interview: "You should interview the spouses in this study; then you'd really find out how miserable these patients are to live with."

In a similar vein, it is possible that the experience of dependency and surrender in personal relationships is threatening to the post-treatment patient in that it bespeaks a return of the vulnerability to illness felt during treatment. It would make sense, then, that self-report measures of death anxiety, somatization, and psychosexual functioning, which are under more conscious control than projective measurement of intimacy motivation, would not be significantly different than in non-patients, because patients would be invested in denying this vulnerability. It is conceivable that this TAT projective test measure was necessary to detect this somewhat subtle but important distinction between cancer survivors and age-matched men. Another study result which is consistent with this was the trend (p <.10) toward patients' displaying a more constricted sexual fantasy life on the DSFI (early stage patients were significantly lower than non-patients, p <.05). There is, then, accumulating evidence for a post-treatment interpersonal withdrawal and constriction which is probably subtle and non-pathological, and therefore indicative of normal psychological adaptation to cancer survival in young men.

Other non-significant patient versus non-patient trends in this investigation included: 1) patients' mean global assessment scores of psychological functioning tended to be lower than non-patients; 2) patients' mean somatization, phobic anxiety, and paranoia BSI subtest scores tended to be higher (more impaired) than those of non-patients; and 3) while patients and non-patients did not differ from each other on the extent of psychological symptomatology in the DSFI (BSI-GSI), both groups scored significantly higher (more impaired) than the test's normative sample, with means differing by one full standard deviation.

The first trend noted speaks for itself: patients off treatment (means within the patient group ordered as predicted) tend toward global psychological dysfunction when compared to an age-matched sample. The fact that the rater was hypothesis-wise, however, casts doubt upon this as an impressive result without corroborating evidence. Some such evidence is suggested, though, by the second and third trends noted above. It is interesting to note that these subtests of the BSI which seem most sensitive to patient/non-patient differences are ones which are disease and recurrence related. Somatization, phobic anxiety, and paranoia are a cluster of symptoms which might depict a chronic state of apprehension and vigilance toward body concerns. This idea, that patients off treatment seem to be engaged in measurable, though subtle and non-pathological, amounts of constant concern over their bodies also received some support in the POR interview. Specifically, 67% of all patients acknowledged feeling distressed over the presence of symptoms which remind them of their illness during the off-treatment period. More than 80% reported a conscious increase in self- and body-awareness with regard to physical health. Nearly half of them have complained of generalized post-treatment physical discomfort, and 57% complained of decreased physical stamina which has lingered on in the months and years following treatment. They also readily admitted that the potential for relapse is a chronic concern of theirs, although this fear does not generally intrude upon their daily functioning.

To summarize, then, it would seem that the patients in this study are living with a chronic, low-grade awareness of their physical vulnerability and life's uncertainty which results in heightened vigilance toward their body. Just as with the apparent lowering of intimacy motivation, this heightening of self-awareness and attention to one's body appears subtle; to an extent which does not seriously threaten the overall psychological health of the successfully treated patient. Putting these two observations together in a simplistic way, one can speculate about a slight retraction of oneself from others and a trend toward increased focusing of oneself upon one's body, during the cancer survival period.

A final comment in this section refers to the observation that patients and non-patients scored one full standard deviation above the BSI normative sample on psychological symptomatology. Three explanations for this will be proffered. One possibility is demographic, that the age and geography of the current sample is different from the normative. Norms for the BSI were collected on a combined urban and suburban population in the Baltimore, Maryland area. Mean age of the normative sample was 45. The study sample was derived from the New York metropolitan and surrounding area. Their mean age was 31. It is conceivable that somewhat higher psychological symtomatology is normative in the faster-paced New York City area. Also, increasing age could be associated with decrease in symptomatology. Both of these demographic explanations are weak, however, because other DSFI and BSI subtest scores did fall within one standard deviation of the normative mean, and because the idea of lessening psychological symtomatology from age 30 to age 45 runs counter to established developmental psychological theory (Levinson, 1978; Vaillant, 1976).

A second possible explanation for elevated psychological symptomatology in both patients and non-patients when compared to normative data is that the small sample size of non-patients has resulted in inflation of the group's mean score owing to the influence of one or two outliers in this small group. While it is true there were two non-patients who scored quite high on the BSI-GSI, the variances of the patient and non-patient samples did not differ significantly, suggesting that this also is an inadequate explanation.

The third possibility would of course be that both patients and non-patients truly have elevated psychological symptom profiles, which fall between normalcy and the mean for the BSI psychiatric outpatient sample. Recalling that the non-patient group was selected by asking patients to pick "men like (themselves), of similar age," this possibility is quite conceivable. The experimenter attempted to be methodologically conservative by selecting non-patient comparison subjects who were "informally matched for similarity" to the patients. Perhaps successful matching has been verified by these mutually elevated symptom profiles. The price paid would then be a false negative study result. This would imply that there is in fact an elevation of psychiatric symptomatology in the successfully treated Hodgkin's patient during the years off treatment.

In summary, the patient to non-patient comparisons revealed little evidence for severe psychopathology in the cancer sample. However, there were clearly some unique concerns and adaptational difficulties within the patient group. Some of these included lowered intimacy motivation, continuation of avoidant thinking toward their illness, and elevation of disease-related concerns. While exploration of these patient to non-patient scores has been of great interest, it was recognized from the inception of the study that separate control of factors such as disease, specific diagnosis, and treatment would be impractical. Thus, patient to non-patient comparisons have been viewed as a relatively loosely controlled inquiry into the general experience of past cancer and treatment taken together. The core of the investigation, however, related to the patient group only. In a more tightly controlled design, the 60 patients were separated into four cells identified by the two (disease severity) by two (time off treatment) factor matrix. This allowed the experimenter to examine closely the effects of disease stage (early vs. late) and time off treatment (recent vs. distant), upon the same dependent measures, within the patient group. The next section will summarize the findings of this more carefully controlled inquiry.

Differences Within the Patient Group

In the most global sense, the preponderance of non-significant findings on self-report measure comparisons would suggest that substantial differences do not exist between early and late stage patients or between patients recently and distantly off treatment. If one were to judge the impact of patient variables solely on the basis of planned significance testing, the conclusion of very little difference would be justified. However, it was noticed that many of the differences between patient groups, while not statistically significant, were in the predicted direction. The two independent variables within the patient sample were disease (or treatment) severity and time off treatment. It was predicted that late stage patients would appear more disturbed than early stage patients, who in turn would appear more disturbed than non-patients. Similarly, it was hypothesized that patients recently off treatment would be the most disturbed, followed by patients distantly off treatment and non-patients, in that order.

The post-hoc binomial _z_ calculations demonstrated, for both independent variables, the presence of a subtle impact. The ordering of mean scores across the three levels (non-patients included) of each independent variable occurred in the predicted direction more often than attributable to chance. Therefore, while not of primary statistical significance, the numerous correct orderings lend indirect support to the hypothesis of mild, subtle impairment in all patients. This impairment would seem to be slightly greater in later stage patients as well as in those patients recently off treatment. It may be that larger sample sizes would be sufficient to boost some of these non-significant trends to significance. Alternatively, these trends may be further evidence for only mild, non-pathological disruption of psychological functioning. This reaffirms the adaptational model of understanding survival, which emphasizes dynamic change within normal limits; change which assimilates external insults and reorganizes internal psychic structures to accommodate new demands (Silberfarb, 1982; Sutherland, 1956; White, 1976).

The self-report measures proved useful in the affirmation of low risk and high risk patient groups, in many cases where early stage patients distantly off treatment (low risk) were compared to late stage patients recently completing treatment (high risk). Global psychological adjustment (GAS score), intrusive thinking about diagnosis and treatment, phobic anxiety, and depressive symptomatology were all significantly more impaired in the high risk group. This appears sufficient to identify late stage Hodgkin's disease patients in the first two years off treatment as at significant risk for measurable psychosocial maladjustment. The reader may recall that the high risk group showed the greatest difficulty returning to full-time work, even when compared to all 45 other patients. The fact that all patients recently off treatment, including early stage patients, rated their current life situation as significantly lower than patients distantly off treatment (and non-patients as well) on the POR Life Scale Rating is considered to be a related but more general result in that it applied to all patients recently completing treatment.

In summary of the low risk-high risk distinction, the study results suggested that disease stage and time off treatment only tended to differentiate patients (as seen in the post hoc binomial z calculation). However, the identification of high and low risk groups based on these two factors in combination was justified on the basis of quality of life and coping style differences. This would suggest an additive effect of these two variables. So, for example, having had severe disease and treatment may not be accompanied by significant disruption three to six years off treatment, but it represents a much more palpable vulnerability in the first two years following treatment. This does not seem to be as clearly the case for earlier stage disease, where fewer dependent measures were elevated, even in the recently-off-treatment condition. The wake of the treatment ordeal does appear to be more problematic for later stage patients.

One exception to this low risk-high risk distinction was the study data on conditioned symptoms. Compared to all early stage patients, all late stage patients had significantly more conditioned nausea to treatment-related stimuli such as rubbing alcohol, perfume, cleaning fluids, and sights of the hospital or clinic setting. This makes clear intuitive as well as theoretical sense, since conditionability has been associated with severity of the unconditioned stimulus, in this case the severity of treatment (Morrow, 1982). Evidence for the tapering, though not elimination, of conditioned nausea over time was provided by the study's determination that patients recently off treatment had far more conditioned nausea than those distantly off treatment. This again confirms intuition and conditioning theory on extinction (Redd, Burish, & Andrykowski, 1983). The removal of the noxious unconditioned stimulus (treatment) results in repeated exposure to the associated (conditioned) environmental cues alone (smells, usually). The passing of time, and repeated exposure to the now-unpaired stimulus (i.e., the conditioned stimulus is experienced alone, without the unconditioned stimulus) results in the depotentiation of the learned associated. Therefore, patients appear to be able to "unlearn" most of their conditioned nausea.

It was mentioned that smells usually mediated the conditioned nausea. This has often been recognized as the chief mediator of conditioned nausea (Love, Nerenz, & Leventhal, 1982; Morrow, 1982; Redd & Andrykowski, 1982). It may in fact be that this smell-mediated conditioning, because it is so visceral in its connection to taste and gustatory function, is not only the most learnable (Love, Nerenz, & Leventhal, 1982) but also the most "unlearnable." This is suggested, in part, because of this study's determination of no reduction over time in conditioned anxiety, which is more sight-mediated. It seems, then, that the gradient of extinction of conditioned anxiety is less steep than that of conditioned nausea. This would imply that, given enough time, the strength of the association between now harmless cues and anxiety will diminish. There are three problems with this argument. First, the constant pairing of conditioned and unconditioned stimuli in treatment would be more likely associated with rapid extinction off treatment because of the weak nature of this pairing schedule. Second, considering that taste aversions are among the most resistant to extinction (Redd & Andrykowski, 1982), one might conclude that this is an example of that principle. The problem with this reasoning is that conditioned nausea, which did show significant extinction, is more taste-mediated than anxiety. There is a third weakness in the conclusion that the anxiety measured in the patient sample represented truly conditioned anxiety which is slow to extinguish. This is that late stage patients (who were treated far more aggressively) were no more anxious than early stage patients. If this were simply a learned response to noxious treatment, one would have expected more aggressively treated patients to have learned more powerful associations to reminders of that treatment, as was the case with nausea. This did not happen with anxiety.

These flaws in the conceptualization of post-treatment anxiety as a conditioned response which is resistant to extinction lead to speculation about an alternative explanation. It may be that post-treatment anxiety is a trait characteristic and therefore evenly distributed across patient groups. That is, patients who are anxious upon entering treatment experience further anxiety in response to cues associated with noxious treatment. This anxiety would not then be expected to diminish significantly over time, because it is as much a reflection of premorbid disposition as it is recent conditioning. Indeed, patients who are more anxious upon entering treatment may be at higher risk for increase and continued elevation of treatment-related anxiety. The data from this study do not resolve this question, so only speculation is possible. It has been shown elsewhere, however, that patients who are anxious upon entering treatment are more easily and more strongly conditioned than those who are less anxious (Holland, 1982b; Love, Nerenz, & Leventhal, 1982).

In summary of the data on conditioned nausea and anxiety, evidence to support lessening of conditioned nausea in less aggressively treated patients and with the passing of time was quite convincing. The data fit very well that which would be predicted by learning theory and previous literature on the factors which contribute to conditioning. On the other hand, the data for conditioned anxiety do not fit this paradigm. Patients were undiscriminable as to disease stage and time off treatment. Given the prevalence of anxiety in the sample, it is suggested that "conditioned" anxiety may in fact better be understood as trait-related anxiety exacerbated by the treatment experience rather than strictly a learned response. Such patients, incidentally, might be expected to manifest more "conditioned" nausea than the non-anxious patients, since pre-treatment anxiety has been associated with increased risk of conditioning while in treatment (Holland, 1982b; Love, Nerenz, & Leventhal, 1982). This is potentially a very fruitful area for future investigation. It would be very useful to know if patients at high risk for extended off-treatment anxiety related to treatment reminders can be predicted on the basis of pre-treatment anxiety.

This section will conclude with a discussion of the prevalence of psychosocial problems surveyed in the patient sample which might relate to depression or negative affects in particular. The term "depressive equivalents" was used in this study to refer to symptoms or difficulties not typically identified by the lay public as reflecting negative affective states. It was hypothesized that whereas patients might deny depression overtly (or even be unaware of it themselves) in an effort to look good, they would have less of an ability to deny depressive equivalents if unable to recognize them as such.

When patients' current off-treatment ratings were compared to their own retrospective in-treatment self-ratings, they were found to be significantly less irritable and depressed, and to be having much less difficulty with sleep and concentration. This is hardly surprising, given the clear disruption to smooth life functioning which treatment can impose. Across-patients comparisons were somewhat different. Patients recently off treatment were no more depressed or symptomatic than those distantly off treatment (Table 9). This runs counter to the conclusion of D'Angio and Ross (1981) which states that psychological distress drops over time. On the other hand, the fact that they were also no <u>less</u> depressed or symtomatic is in disagreement with other findings (Derogatis et al., 1979; Rogentine et al., 1978). Thus, this study's results of patient ratings on "depressive equivalents" suggested neither increase nor decrease of symptomatology over time or across disease severity.

While there is no way of confirming this with normative or comparison group data, the frequencies of patient symptomatology seem high. An incidence rate of 57% complaining of decreased stamina is striking, although not as high as the Greenleigh Associates' (1979) 93% figure. This is especially significant in light of the oncologist's contention that toxic chemotherapeutic and radiologic physical aftereffects should be eliminated within the first six months off treatment. Sleep disturbance and concentration difficulty were problematic in just over one-quarter of the patient sample (27% each). The fourth "depressive equivalent," eating habits, was only problematic in 13%, and had actually improved in 21% of patients. One speculative explanation for high incidence of fatigue, sleep difficulty and concentration difficulty, along with low incidence of eating disturbance is that of the four functions mentioned, eating is the one which probably has the most conscious control. Thus, the recovered patient, in an attempt to "do something" in order to adapt to his situation and counteract chronic uncertainty and potential dysphoria, might embark on a course of improved nutrition. Frequently, patients would comment that they had made concerted efforts to continue their struggle against poor health in general and relapse in particular by seeking nutritional consultation and change in eating habits. Eating well is something they can do to stay healthy (and deny dysphoria), while sleeping well, feeling strong, or concentrating effectively are not so easily done.

The exploration into depressive equivalents was undertaken as an indirect inquiry into negative affects in the surviving cancer patient.

It appears that adaptation to cancer is truly multidimensional and it is therefore difficult to identify clear generalizations. The experiences of diagnosis, treatment, and then extended remission constitute major events with probable far reaching consequences. In order to highlight this conclusion, the next section will present three brief case vignettes which exemplify the different vicissitudes of adaptation and adjustment. This will be followed by the final section which makes suggestions for future research.

Case Examples

The first gentleman, John (a pseudonym), is a 32-year old single man, three years off treatment for late stage illness. By his own description, he was an anxious, self-involved "neurotic" prior to his illness, who had been in psychoanalytic psychotherapy for two years before diagnosis. He had many friends but felt close to nobody. During treatment he was extremely anxious and fearful of death. He developed severe anticipatory nausea and vomiting. As he began to get positive signs from his physician, that he was free of any evidence of disease, for example, he started to feel quite proud of himself and internally strengthened. When treatment ended, he threw himself into his career as a film maker and teacher. He cut off contact with many acquaintances and focused his energies into deepening friendships which were more important to him. After agreeing with his therapist, he terminated his therapy one year after cancer treatment ended, resolving that he had accomplished a satisfactory amount.

John rated himself presently as more self-confident and content than ever in his life. As he put it, "the sense of worth I got from beating this illness taught me to like myself more and accept myself. I'm not so picky about things anymore. And I choose my friends differently now. I look for respect and support." This vignette no doubt paints a positive adaptational picture. However, there was evidence of continued conflict in the area of fertility. During the interview, he joked that the experimenter's questions about his infertility and desire for children were upsetting the balance he had achieved to date: "I'm not ready to deal with that one yet," he said. "It's still a budding issue for me now, so I can't talk about it too much or it'll upset me and it will be your fault (laugh)."

The second case is a 39-year old married man with three children who will be called Michael. Michael is a man with early stage disease, off treatment for seven years. He has a long premorbid history of chronic dysphoria and low self-esteem. His father was an alcoholic and mother was described as particularly ungiving, demanding, and unaccepting. Michael was married and had three children at the time of diagnosis. He was a passive, dutiful husband who felt trapped in an office job which he loathed but could never leave because of his sense of responsibility. As he put it, "I have always felt that my purpose in life was to do people favors and keep them happy."

When Michael heard of his diagnosis he hardly reacted. "I just figured I'd see what would happen. It didn't really upset me, I took it in stride." During treatment he became fascinated with the technology of the radiation therapy equipment, and this fascination fueled a career change. When treatment ended, he went on public aid (against his wife's wishes) so that he could study nuclear medical technology:

"It was the first thing I really did just for me. No one could understand it, but like one of my friends told me, it's too bad I had to almost die to get out of the work I hated." Michael's essentially dysphoric character was relatively unchanged by the impact of cancer and treatment, but the cancer experience did apparently free him from the long-felt shackles of job dissatisfaction. He is now a successful nuclear medical technologist.

The third case example, Timothy, is a 29-year old physician with early stage disease, 11 months off treatment. Timothy is single and lives with his parents and younger brother in a suburban home out of which he practices. He agreed to participate in the study because he felt he owed it to his treating physicians, but the prospect of discussing his reactions to his illness frightened him. He had no significant premorbid psychiatric history, but has had a spectrum of difficulties which began in treatment and have persisted until the time of the interview. For instance, the repeated intrusion of suicidal ideation while driving his car and standing in high places troubled him during the treatment and early post-treatment periods. Related to this obsessional reaction was the recent emergence of a need to be sure all his bureau drawers are closed whenever he gets an article of clothing. Symptoms such as this emerged unpreceded by evidence of a premorbid obsessive-compulsive disorder. Recurring nightmares with repressed content also still occurred once or twice per month. When asked how he knew the nightmare was recurring if he could not recall the content, Timothy explained that the feeling he has upon awakening is the same. When he wakes up from these nightmares, his thoughts are invariably "of cancer and death."

In a follow-up phone call to Timothy two weeks after the interview, he stated that the interview and testing were difficult experiences for him. The three-hour session revived intense anxiety feelings he had just begun to master in the past three to six months. He added that the disturbance he felt from the interview was ephemeral, lasting two to three days, and that things were now back to normal. "Normal" for him is a state of steady reorganization and restabilization which finds him gradually able to be more focused on his work and personal life as time goes on. His practice had been cut to three days per week, but he hoped to be up to full time within another year.

One can see from these three case examples that the impact of cancer and treatment is not universally similar and is largely determined by personal character and predisposition as well as life circumstances. As the study data also indicated, it is difficult to accurately generalize about the cancer experience. Much of adaptation to survival seems to be determined by individual differences in coping style and interpretation of the meaning which the illness carries. Future research in this area could be very useful in more clearly identifying the factors contributing to poor adjustment to cancer survival. Some suggestions for further investigation are offered in the next section.

Suggestions for Future Research

The results of this study, as well as the literature review which preceded them, point to certain need for further investigation into the area of psychosocial adaptation to cancer survival. This study attempted to add to the fast-growing base of data by introducing the following unique characteristics: Focused study of a single diagnostic group and sex; and isolation and examination of the effects of disease stage and time off treatment upon adaptation to survival. It would be quite valuable, then, to extend the inquiry, first to female Hodgkin's disease patients, then to other age groups in order to determine the replicability and generalizability of this study's findings. Second, it would be useful to study other diagnostic cancer groups, preferably those with comparably favorable prognoses first. It will then become interesting to study survivors of poor prognosis cancers, to see if they might look more psychologically troubled.

It has been emphasized that patient-wide generalizations about the long-term sequelae of successful cancer treatment are difficult to make. Some of the patient variables which seem to contribute to adaptation are the meaning which the patient ascribes to the cancer experience and the defensive characteristics and coping styles which they employ. It would be useful to isolate these variables and compare patient adaptation across them.

More specific study suggestions include replication and refinement of the major results of the current investigation. The lowered readiness of cancer survivors to engage in warm, personal relationships has potentially far-reaching implications. It would be useful to determine whether this lowered intimacy motivation is indeed associated with a heightened attention to one's body and a sense of physical vulnerability; or if it is related to a counterdependent reaction against the passivity of the patient role, or both.

Another study result which could benefit from further investigation was the determination that conditioned nausea tended to follow a predictable course of decline, based upon knowledge of disease stage and length of time off treatment. However, the same was not true for so-called "conditioned anxiety." If, in fact, post-treatment anxiety in response to associated environmental cues is more a reflection of trait susceptibility than associative learning, there may be only insignificant lessening of disease- and treatment-related anxiety in the post-treatment period. It would therefore be beneficial to identify these high risk patients during the treatment period, so that preventive measures could be taken early. Perhaps high pre-treatment anxiety will show itself to be a reliable predictor of continued post-treatment "conditioned" anxiety.

SUMMARY

This study examined the psychological functioning of 60 men, aged 20-47, who had been treated for Hodgkin's disease, and compared them to an age-matched sample of 20 physically healthy men. All patients were off treatment and free of any sign of disease for at least six months. Besides the cancer variable, the independent variables of interest (within the patient group) were disease stage (early vs. late) and time off treatment (6-24 months vs. 30 or more months). There were 15 patients in each of the four groups comprised by the above two variables. Cancer survivors were expected to show heightened psychological disturbance due to the prolonged stress of diagnosis and severe treatment, and because of uncertainty about the future. Within the patient group, those with later stage disease and those recently completing treatment were hypothesized to show greater disturbance. Dependent variables of interest were psychosexual functioning, psychiatric symptomatology, intrusive and avoidant thinking toward the past stressor of diagnosis, self-esteem, death anxiety, global psychological adjustment, intimacy motivation, and interview ratings of psychosocial problems and quality of life.

Patients were compared to non-patients and to themselves across the variables of disease stage and time off treatment, in a 2x2+1 factorial ANOVA design. The hypothesis of greater psychosocial morbidity in the general cancer sample was partially confirmed by the significantly lowered intimacy motivation scores and a trend toward more constricted sexual fantasy lives in the cancer patients. Patients also showed

significantly more avoidant thinking toward the stressful event of their diagnosis than the non-patients (NP's) did toward self-selected past stressors. Patients tended to appear more disturbed than NP's on many self-report and interview measures, as indicated by the frequent predicted ordering of non-significant mean differences. On the other hand, all patients were significantly more appreciative of life than NP's. It was concluded that disease stage and time off treatment were important variables in the post-treatment adaptation of successfully treated male Hodgkin's patients. The identification of "low risk" and "high risk" groups suggested a possible additive impact of disease severity and recent treatment cessation. A dramatic study result was the lessening of treatment-related nausea over time and across disease stage. The same was not true of "conditioned anxiety," suggesting it may be trait-related anxiety exacerbated by treatment and its reminders.

It was concluded that the experience of cancer survival does seem to carry with it heightened psychosocial risks which do not generally extend beyond the boundaries of normal adaptation. However, there was some suggestion that extended remission also brings significant life appreciation and perhaps even character growth. Thus, generalizations about cancer survival are difficult to make, as adaptation seems to be strongly influenced by individual differences.

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APPENDIX A

PROBLEM ORIENTED RECORD
(revised)

ID NUMBER ________________ DATE ________________

Place of interview: ________________ Interviewer: ________________

N/A = not applicable
DK = don't know
R = refuse answer
S/O = significant other
1-10 = patient's rating of severity, on a 1 to 10 scale, with 1 being "not at all a problem," and 10 being "an extremely severe problem."

Chart Data:
diagnosis date: ________
birth date: ________
age at diagnosis: ________
date treatment began: ________
date treatment ended: ________
Diagnosis: ________
Stage: ________
Months off treatment: ________

Treatment info (chart) ________________

THE FIRST THING I NEED TO DO IS GET SOME SPECIFIC FACTS FROM YOU, LIKE YOUR BIRTHDATE, FOR EXAMPLE.

1. SEX ________

2. DATE OF BIRTH ________ 3. AGE ________

4. Ethnicity:
white ________
black ________
hispanic ________
oriental ________
other (specify) ________

5. Marital Status and Dates:

never married ______ living with anyone? ______ # years: ______
married once ______ for how long? ______
married 2 or more ______ separation/divorce dates: ______ # yrs new marriage: ______
divorced ______ when? ______ new s/o? ______
separated ______ when? ______ new s/o? ______
widowed ______ when? ______ new s/o? ______ Cause of spouse's death: ______

Spouse/ s/o occupation (even if deceased): ________________
Age of spouse: ______

6. SIBLINGS

Name	Sex	Age (indicate any deaths)
________________	____	____
________________	____	____
________________	____	____
________________	____	____

7. PARENTS: Mother: alive ____
dead ____ cause:__________ when:_____(age)_____

Father: alive ____
dead ____ cause:__________ when:_____(age)_____

Living together? __________

8. CHILDREN:

Name	Sex	Age	Financially Dependent	Financially Independent

9. Education:

no formal education / some graduate school ________
grammar school graduate ________
high school graduate / equivalency ________
some college ________
college graduate ________
some graduate school ________
graduate/professional degree ________

10. Current occupation: ______________ Same as before illness? __________

full time:____ paid leave: ______ disability/
part-time:____ unpaid leave:______ public assistance:______
hrs./week:_____ looking for work: yes___ amount: __________
no___
SES: 0-10__ 10-20__ 20-30__ 30-50__ 50+__
(in thousands) if married, include spouse.

hrs work pre-ill? ____/wk
hrs work in tx? ____/wk

11. Whom do you now live with and what are their relationships to you?

____

____

12. Religion? __________________

Practicing? Yes____ No____ # of times been to service in past month:______

Can you tell me your diagnosis? ____________________ Stage? ________

13. What serious illnesses, injuries, etc., have you had?
(indicate any that occured after initial diagnosis with an "*".)

What	Dates	Hospitalized?	After Dx?

Do you remember when your illness was first diagnosed? ______________

Who told you? ______________ Where was it? ______________

What were the circumstances that led up to this? ______________

____

When did *you* first notice something was wrong? ______________

When did you first consult a physician? ______________

What were your symptoms then? ______________

____

What was the initial medical treatment before diagnosis? ______________

____

How upset were you about these symptoms at that time? (1-10) ________

What was your reaction when you were told your diagnosis? ______________

____

FOR THE FOLLOWING QUESTIONS, PLEASE RESPOND IN TERMS OF THE TREATMENT YOU RECEIVED FOR YOUR ILLNESS.

Were you hospitalized at all during your medical workup or treatment? ____

(if yes) When and for what? ____________________ How long? ______

When did you start actual treatment? __________ When finish? __________

What treatment did you have for your illness? ______________

____

Surgery? No___ Yes___ What was done? ______________________________

______________________________ Physical discomfort severity?(1-10) ______
How upsetting? (1-10) _____

Chemotherapy? No___Yes___ What drugs do you remember? ____________________

______________________________ Physical discomfort severity?(1-10)_____
How upsetting?(1-10)_______

Radiation? No___ Yes___ Where?______________________________

How long/how many times? _____________Physical discomfort severity?(1-10)___
How upsetting?(1-10)______

Any other treatment (e.g., other medicine, transfusions, etc.)? No___ Yes___

What? ______________________________ Physical discomfort severity?(1-10)____
How upsetting?(1-10)_____

Overall, how much distress did the treatment itself cause you?(1-10)_____

Please rate the physical discomfort (1-10) and level of distress (1-10) which any of the following possible side effects of treatment may have caused you (1 = none, 10 = very severe):

tiredness/weakness	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
nausea/vomiting	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
diarrhea	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
appetite/weight loss	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
hair loss	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
mouth sores	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
sexual problems	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
numbness/tingling	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
fever/chills	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___
bad taste in mouth	No__	Yes__	Physical discomfort?(1-10)___	Upsetting?(1-10)___

8. Did you find the general hospital care to be a problem, e.g., admitting procedures, etc? No__ Yes__ How much of a problem?(1-10)_____

10. Did you find the care given by the nursing staff to be a problem (e.g., long waits for service, indifference, etc.)?No__ Yes__ How much a problem?(1-10)_____

43. Was taking time off from your home activities to be in treatment a problem?
No__ Yes__ How much a problem?(1-10)_____ How many days? ____________________

Was taking time off from work to be in treatment a problem for you?
No__ Yes__ How much a problem?(1-10)_____ How many days? ____________________

97. Was the treatment a difficult experience in general for you?
No__ Yes__ How much of a problem? (1-10) _____

68. Did you have any financial burdens as a result of your treatment or illness?
No__ Yes__ How much a problem?(1-10) _____ Still in debt? No__ Yes__

What % of medical expenses were paid for by insurance/public assistance?
0%___ 5-25%___ 26-50%___ 51-75%___ 76-95%___ 100%___

Did your illness or treatment result in a loss of job or income for you?
No__ Yes__ Explain____________________ How much a problem?(1-10)_____

117. While in treatment, did you experience yourself as being more irritable or on edge in your relations with people?
No__ Yes__ How much a problem?(1-10)_____

116. While in trea-ment, did you go through periods of feeling low, down, or blue? No__ Yes__ How long (% of time)?________ How much a problem?(1-10)_____

119. While in treatment, did you have any trouble sleeping?
No__ Yes__ How long (% of time)?_________ How much a problem?(1-10)_____

121. While in treatment, did you have any trouble concentrating?
No__ Yes__ How long (% of time)?_________ How much a problem?(1-10)_____

While in treatment, did you ever take any medicicine for your mood or sleep?
No__ Yes__ What/how long? ______________________________

During the treatment period (including pre-treatment wait), did you have any contact with a professional counselor (e.g., psychiatrist, psychologist, social worker, clergy)?
No__ Yes__ How much?______________ For what?______________________

IF S/O:

73. While in treatment, were there any changes in your relationship with your spouse (s/o)? No__ Yes__ What?______________________________________
__________________________ How much a problem?(1-10)_____

70. Did you talk to your spouse (s/o) about what was wrong with you?
No__ Yes__ Was it helpful?__________

Did your sex life change during treatment? No__ Yes__ How?______________
_________________________________ How much a problem?(1-10)_____

IF NO S/O:

Did your dating habits during treatment change? No__ Yes__ How?__________
__________________________________ How much a problem?(1-10)_____

Did your sex life change during treatment? No__ Yes__ How?______________
__________________________________ How much a problem?(1-10)_____

ALL:

Was there any other major life change you experienced while you were in treatment? No__ Yes__ What?____
_________ How much a problem then?(1-10)_____ Problem now?(1-10)______

NOW I'D LIKE TO ASK YOU SOME QUESTIONS ABOUT YOUR DOCTOR(S):

Who was your main doctor during your treatment?_____________________

Same as your follow-up doctor?_____ if no, follow-up M.D.:_____________

Did your treating doctor explain your illness and treatment to you?______

What would you say about the amount of information given to you by the doctor who explained the treatment?

___far too much for me to absorb
___somewhat more than necessary
___just about the right amount
___not quite enough
___far too little

Please rate your treating doctor (1-10) on each of the following qualities:

Understanding of my feelings (1-10)_____
Available to talk to (1-10)_____
Informative about my illness and treatment (1-10)_____

NOW I'D LIKE TO SHIFT OUR DISCUSSION TO THE PERIOD BETWEEN THE END OF YOUR TREATMENT AND RIGHT NOW.

Since you completed treatment, have you noticed any symptoms that have concerned you? No__ Yes__ What?______________________________________

115. How concerned are you about what is wrong with you now?(1-10)_____

Has your doctor been concerned about a recurrence or other serious complication? No__ Yes__ When and What?_____________________________
____

Have plans for follow-up after treatment been a problem for you?

No__ Yes__ In what way?____

______________________________ How much a problem?(1-10)_____

Have there been times when you have felt left on your own (abandoned) by your doctor or the hospital staff since you completed treatment?

No__ Yes__ How much a problem?(1-10)_____

How often do you come in for follow-up?________________________________

What medical procedures have been done since you have been off treatment? (e.g., x-rays, blood tests, angiograms, etc.) ____________________________

____

____

96. Did you find these procedures upsetting in any way?

No__ Yes__ How upsetting?(1-10)_____

108. What other procedures are you expecting to undergo?______________________

____

How worried are you about them?(1-10)_____

2. Have you experienced any physical discomfort since ending treatment?

No__ Yes__ When?____________________ Any in past month?_________

How much of a problem?(1-10)_____

116. Since completing treatment, have you experienced feeling low, down, or blue? No__ Yes__ When?________________in the past month?____________

How upsetting?(1-10)_____

Since completing treatment, have you ever thought of hurting yourself on purpose? No__ Yes__ When?______________ Ever before?____________________

Have you taken any medication for pain, mood, or sleep since completing treatment? No__ Yes__ Pain__ what?________________ in past month?_______

Mood__ what?________________ in past month?_______

Sleep__what?________________ in past month?_______

117. Since completing treatment, have you ever experienced yourself as being more irritable or on edge in your relations with people?

No__ Yes__ How much a problem?(1-10)_____

75. Have you had any sexual difficulties? No__ Yes__ How much problem?(1-10)_____

76. Is your sex life what you'd like it to be? No__ Yes__ Problem?(1-10)_____

IF S/O:

Is your sex life what your partner would like it to be? Yes__ No__
How much a problem for you?(1-10)_____ for partner?(1-10)_____

73. Do you find any changes in your relationship with your partner since you completed treatment? No__ Yes__ What?________________________________
________________ How much a problem?(1-10)_____

69. Has your partner's reaction to your illness been a problem in any way?
No__ Yes__ How?________________ ________________ Problem?(1-10)_____

Are you talking to your partner about what was wrong with you?

No__ Are there times you would like to talk and find you can't?
No__ Yes__ How disturbing is (was) this for you?(1-10)_____ (70)

Yes__ Is it helpful? No__ Yes__ How disturbing is this?(1-10)_____ (71)
Are there times you would like to talk and find you can't?
No__ Yes__ How disturbing is (was) this for you?(1-10)_____ (72)

IF NO S/O:

87. Have there been any changes in your pattern of dating since treatment ended? No__ Yes__ What?________________________________
________________ How much a problem?(1-10)_____

ALL:

FAMILY (excluding s/o)

77. Has your family's reaction to all this been a problem for you in any way?
No__ Yes__ How much a problem now?_____ How much problem before?(1-10)_____

Are you talking to your family about what was wrong with you?

No___ Are there times you would like to talk and find you can't?
No__ Yes__ How disturbing is this?(1-10)_____ (78)

Yes__ Is it helpful? Yes__ No__ How disturbing is this?(1-10)_____ (79)
Are there times you would like to talk and find you can't?
No__ Yes__ How disturbing is this?(1-10)_____ (80)

84. Has there been a change in your role in your family as a result of your illness? No__ Yes__ What?________________________________
________________ Problem?(1-10)_____

85. Do you find any changes in your relationships with family members as a result of your illness? No__ Yes__ With whom and what?________________
________________________________ Problem?(1-10)_____

FRIENDS

94. Have your friends' reactions to your illness and treatment been a problem for you in any way? No__ Yes__ How?______________________________

______________________________Problem now?(1-10)_____

Are you talking to your friends about what was wrong with you?

No___ Are there times you would like to talk and find you can't?
No__ Yes__ How disturbing is this for you?(1-10)_____ (88)

Yes__ Is it helpful? Yes__ No__ How disturbing is this?(1-10)_____ (89)
Are there times you would like to talk and find you can't?
No__ Yes__ How disturbing is this for you?(1-10)_____ (90)

Has there been a change in <u>your role</u> (or <u>relationships</u>) with friends as a result of your illness? No__ Yes__ How?______________________________

______________________________ Problem?(1-10)_____

Did your doctor describe future possible risks to your health which might result from treatment? No__ Yes__ What?______________________________

____

(if not mentioned)... mentioned(x)

Recurrence? No__ Yes__ How upsetting?(1-10)_____ _____
Future illness (2nd malignancy)? No__ Yes__ How upsetting?(1-10)_____ _____
Organ failure? No__ Yes__ How upsetting?(1-10)_____ _____
Infection? No__ Yes__ How upsetting?(1-10)_____ _____
Sterility? No__ Yes__ How upsetting?(1-10)_____ _____
Other?______________________________ How upsetting?(1-10)_____ _____

Overall, how much distress did hearing of these risks cause you at that time?(1-10)____

How much distress do they cause you now?(1-10)_____

What, if any, bodily change has occurred as a result of your surgery (treatment)?
______________________________Problem?(1-10)_____

How has it affected your sexual activity?______________________________
Has this been a problem for you? No__ Yes__ (1-10)_____
How about for your partner? No__ Yes__ (1-10)_____

What exactly were you told about your future capacity to father children?______

____

What is your current potential to father children (excluding sperm banking)? ____

Since your treatment ended, have you had any tests (e.g., sperm counts) to see if you could have children? No__ Yes__ Results?____________________

How much of a problem is this for you?(1-10)____ for your s/o?(1-10)____

Were you offered sperm-banking before treatment began?____________________

if yes, did you accept? No__ Yes___

Have you had any children since treatment ended? No__ Yes__

if yes, through sperm banking? No__ Yes__

Are you interested in having (more) children?

No___ reason:a___already have enough
b___never wanted children
c___wanted once but changed mind
if c...did you change your mind because of illness?___

Yes__ What are your plans?______________________________

FOR THE NEXT GROUP OF QUESTIONS, COMPARE YOUR LIFE <u>BEFORE THE FIRST SIGN OF YOUR ILLNESS</u> TO <u>RIGHT NOW</u>:

29. Compared to life before your illness, has there been a change in the activities you enjoy doing alone? No__ Yes__ How much of a problem?(1-10)_____

30. Compared to life before your illness, has there been a change in the activities you enjoy doing with your family? No__ Yes__ How much a problem?(1-10)_____

31. Compared to life before your illness, has there been a change in the activities you enjoy doing with your friends? No__ Yes__ How much a problem?(1-10)_____

32. Compared to life before your illness, has there been a change in your usual housework routine? No__ Yes__ How much a problem?(1-10)_____

36. Compared to life before your illness, has there been a change in your own ability to do personal care? No__ Yes__ How much a problem?_____

Compared to life before your illness, has there been a change in your physical abilities (e.g., running, walking)? No__ Yes__ Problem?(1-10)_____

38. (if children) Compared to life before your illness, has there been a change in your usual child raising activities? No__ Yes__ Problem?(1-10)_____

81. Compared to life before your illness, has there been a change in your interactions with family (excluding s/o)? No__ Yes__ Problem?(1-10)_____

83. Compared to life before your illness, has there been a change in the number of phone calls/letters with family? No__ Yes__fewer?____ Problem?(1-10)____

91. Compared to life before your illness, has there been a change in your interactions with friends? No__ Yes__ How much a problem?(1-10)_____

93. Compared to life before your illness, has there been a change in the number of phone calls/letters with friends? No__ Yes__ fewer?____
How much a problem?(1-10)_____

119. Compared to life before your illness, have you had a major change in sleeping habits? No__ Yes__What________________________Problem?(1-10)_____

120. Compared to life before your illness, have you had a major change in eating habits? No__ Yes__What________________________Problem?(1-10)_____

121. Compared to life before your illness, have you noticed a change in your concentrating ability? No__ Yes__What___________________Problem?(1-10)_____

50. (if employed/in school) Compared to life before your illness, has taking time off from work or school been a problem? No__ Yes__ How much?(1-10)____
still a problem? No__ Yes__ How much?(1-10)_____

43. Compared to life before your illness, has taking time off from your home or other activities because of your health been a problem for you?
No__ Yes__ How much of a problem?(1-10)_____

68. Do you feel that you currently have any financial burdens because of your illness and treatment? No__ Yes__ How much a problem?(1-10)_____

Have you begun contact with a professional counselor (psychiatrist, psychologist, social worker, clergy) since treatment ended?
No___ Do you feel it would be helpful? No__ Yes__ In what way?______________
____
Yes__ For what problem?______________________________________
How much/long?______________________ Helpful?__________________________

IF EMPLOYED

Did your career plans change as a result of illness?_____________

51. Are your work responsibilities different from before your illness?
No__ Yes__ less responsibility? No__ Yes__ How upsetting?(1-10)_____
Job before illness?______________________ Job now?_____________________
Same company?_________________________Same field?______________________

52. Does your current employer know about your illness? No__ Yes__ if yes or no: Problem?(1-10)___

53. Does your employer treat you any differently because of your illness?
No__ Yes__ How upsetting is this for you?(1-10)_____

if yes or no:
54. Do your co-workers know about your illness? No__ Yes__ Problem?(1-10)_____

55. Do your co-workers treat you any differently because of your illness?
No__ Yes__ How upsetting is this for you?(1-10)_____

IF LOOKING FOR WORK

56. Are you encountering any difficulties in looking for work due to your illness? No__ Yes__ How much of a problem?(1-10)_____

58. Are you experiencing any difficulties with employment agencies or prospective employers due to your illness? No__ Yes__ How much a problem?(1-10)_____

57. Are you telling prospective employers or employment agencies about your medical condition? No__ Yes__ How much of a problem?(1-10)_____

59. Do you need to acquire a new skill or retraining of any kind due to your illness? No__ Yes__ How much a problem?(1-10)_____

IF NOT WORKING OR RETIRED DUE TO ILLNESS

60. How much of a problem is it for you not to be working?(1-10)_____

IF NOT WORKING - IN SCHOOL

61. Did you lose any time from school/training due to your illness? No__ Yes__
Explain____ Problem?(1-10)_____

63. Does the school administration (including teachers) treat you any differently due to your illness? No__ Yes__ How much of a problem?(1-10)_____

65. Have you told your school administration about your medical condition?
No__ Yes__ in either case, how much a problem?(1-10)_____

64. Do your classmates treat you any differently due to your illness?
No___ Yes___ How much a problem?(1-10)_____

62. Do your classmates know about your illness? No__ Yes__ Problem?(1-10)_____

66. Have you had to change your career plans due to your illness?
No__ Yes__ How much a problem?(1-10)_____still a problem?________________

I'D LIKE TO ASK YOU JUST A FEW GENERAL QUESTIONS BEFORE WE STOP.

How has the experience of your illness and treatment affected your outlook on life?____

Do you feel that you appreciate life and just being alive more fully than you did before your illness? No__ Yes__ How much more?(1-10)_____

Are you more likely to see people around you as worried over petty or trivial things, as a result of your experience with your illness? No__ Yes__

do you get impatient with them? No__ Yes__Problem?(1-10)_____

How serious did (do) you feel your illness was (is):

1. When you were told your diagnosis?(1-10)_____
2. When you were awaiting treatment? (1-10)_____
3. When you were getting treatment? (1-10)_____
4. Now (1-10)_____

1 = not at all serious

10 = extremely serious (life and death)

What are your plans for the future? ____

____

How much has your illness affected your plans?(1-10)_____

Do you talk to your partner (or close family if no partner) about the future?

No__ Yes__ (in either case) How much a problem?(1-10)_____

Are there any problems we haven't touched on yet?_______________________________

During work-up?__________________________________How much problem?(1-10)_____

During treatment?________________________________How much problem?(1-10)_____

After treatment?_________________________________How much problem?(1-10)_____

Right now?_______________________________________How much problem?(1-10)_____

Any other comments?____

____

LIFE SCALE

IF A "0" MEANT THAT YOUR LIFE WAS JUST THE WAY IT WAS BEFORE YOU WERE ILL, AND A "+10" MEANT THAT EVERYTHING WAS TOTALLY DIFFERENT AND BETTER, AND A "-10" MEANT THAT EVERYTHING WAS TOTALLY DIFFERENT BUT WORSE, WHERE WOULD YOU PLACE YOURSELF ON SUCH A SCALE?

-10 9 8 7 6 5 4 3 2 1 0 1 2 3 4 5 6 7 8 9 +10

Different but worse Same as before different but better

CONDITIONED NAUSEA/VOMITING/ANXIETY:

Stimulus	Nausea? tx	 now	Vomiting? tx	 now	Anxiety? tx	 now	explanation
smell							
clinic (waiting room or chemo room)							
other? (food, sight or sound?)							

Do little aches and pains upset you more now than they used to before your illness? No__ Yes__ Problem?(1-10)_______

Do you check over your body moreso now than you used to? No__ Yes__
Problem?(1-10)_______

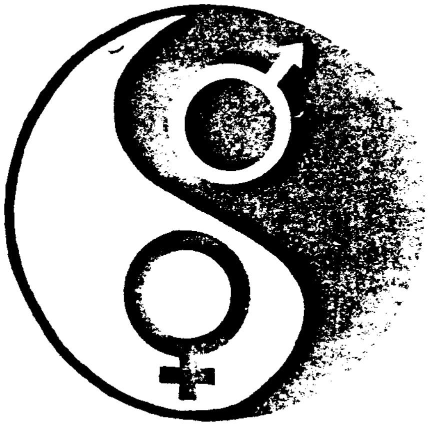
How worried are you about recurrence?(1-10)____

If you do have a recurrence, and your doctor recommends returning to treatment, will you:

_____definitely go back
_____probably go back
_____really couldn't say (could go either way)
_____probably not go back
_____definitely not go back

APPENDIX B

DSFI



DEROGATIS
SEXUAL FUNCTIONING
INVENTORY

INSTRUCTIONS

Below you will be asked to report certain attitudes and opinions, and provide information about some of your sexual experiences. These questions are focused on your thoughts and feelings. Your answers and responses will be kept in the utmost confidence, and only those members of the staff directly involved with your treatment will have access to this information. It will not be made available to anyone else unless you request it. The inventory is divided into 10 sections, and in each section you are asked something slightly different. In some you are asked to answer questions, while in others you are asked to describe yourself. We also ask about problems you may be having and about some of your sexual thoughts, fantasies, and experiences.

Each section has a brief instruction which will tell you what you are to do in that section. Please work quickly, and do not skip any items. If you have any questions, please ask the technician to help you.

SECTION I

Below are some statements concerning general information about sexual functioning. Please read each statement carefully. Once you have read it, indicate whether you agree with the statement or not by marking TRUE *for those you agree with, and* FALSE *for those you do not.*

		TRUE	*FALSE*
1.	USUALLY MEN ACHIEVE ORGASM MORE QUICKLY THAN WOMEN	○	○
2.	HAVING INTERCOURSE DURING MENSTRUATION IS NOT A HEALTHY PRACTICE	○	○
3.	THE PENIS MUST BE ERECT BEFORE EJACULATION MAY OCCUR	○	○
4.	SIMULTANEOUS ORGASM IS NOT NECESSARY FOR A GOOD SEXUAL RELATIONSHIP	○	○
5.	MASTURBATION BY EITHER PARTNER IS AN INDICATOR OF POOR MARITAL ADJUSTMENT	○	○
6.	A WOMAN WHO HAS HAD A HYSTERECTOMY CAN NO LONGER EXPERIENCE ORGASM	○	○
7.	MEN REACH THE PEAK OF THEIR SEXUAL DRIVE IN THEIR LATE TEENS WHILE WOMEN REACH THEIR PEAK DURING THEIR 30'S	○	○
8.	A WOMAN CAN BECOME PREGNANT DURING MENSTRUATION	○	○
9.	MOST MEN AND WOMEN LOSE INTEREST IN SEX AFTER AGE 60	○	○
10.	A MALE'S ORGASM IS MORE SATISFYING THAN A FEMALE'S ORGASM	○	○
11.	THE PROPHYLACTIC (RUBBER) PROTECTS AGAINST CONCEPTION AND AGAINST VENEREAL DISEASE	○	○
12.	LUBRICATION IN THE FEMALE SHOWS SEXUAL EXCITEMENT LIKE THE MALE'S ERECTION	○	○
13.	ORAL-GENITAL SEX IS UNHEALTHY BECAUSE IT ENHANCES THE POSSIBILITY OF CONTRACTING VENEREAL DISEASE	○	○
14.	WOMEN WHO HAVE FANTASIES DURING INTERCOURSE ARE DISSATISFIED WITH THEIR SEX LIVES	○	○
15.	FREQUENCY OF INTERCOURSE IS AN ACCURATE MEASURE OF SUCCESS OF A RELATIONSHIP	○	○
16.	A WOMAN MAY BE BROUGHT TO ORGASM BY MANUAL STIMULATION OF HER GENITALS	○	○
17.	MENOPAUSE IN A WOMAN CREATES A SHARP REDUCTION IN HER SEXUAL DRIVE	○	○
18.	WOMEN DESIRE SEX ABOUT AS FREQUENTLY AS MEN	○	○
19.	AN EFFECTIVE FORM OF CONTRACEPTION IS DOUCHING AFTER INTERCOURSE	○	○
20.	AFTER INTERCOURSE THERE IS A PERIOD WHEN A MAN CANNOT RESPOND TO SEXUAL STIMULATION	○	○
21.	FEMALES CAN MAINTAIN A SEXUAL RESPONSE THROUGH MULTIPLE ORGASMS	○	○
22.	MOST WOMEN ARE ABLE TO ENJOY SEX EVEN WITHOUT EXPERIENCING ORGASM	○	○
23.	THE BIGGER THE PENIS THE MORE SATISFYING IT IS TO THE FEMALE IN INTERCOURSE	○	○
24.	A WOMAN CAN NO LONGER BECOME PREGNANT ONCE MENOPAUSE HAS BEGUN	○	○
25.	ERECTION IN THE MALE IS BROUGHT ABOUT BY CONGESTION OF BLOOD IN THE PENIS	○	○
26.	THE CLITORIS IS NOT A PARTICULARLY SENSITIVE AREA OF THE FEMALE'S GENITALS	○	○

SECTION II

Below are a list of sexual experiences that people have. We would like to know which of these sexual behaviors you have experienced. Please indicate those experiences you have personally had by placing a check ([✓]) under the YES column for that experience. If you have not had the experience place your check under the NO column. In addition, if you have had the experience during the past two months please place an additional check under the column marked PAST 60 DAYS. Make your marks carefully and do not skip any items.

	YES	NO	PAST 60 DAYS
1. MALE LYING PRONE ON FEMALE (CLOTHED)	☐	☐	☐
2. STROKING AND PETTING YOUR SEXUAL PARTNER'S GENITALS	☐	☐	☐
3. EROTIC EMBRACE (CLOTHED)	☐	☐	☐
4. INTERCOURSE-VAGINAL ENTRY FROM REAR	☐	☐	☐
5. HAVING GENITALS CARESSED BY YOUR SEXUAL PARTNER	☐	☐	☐
6. MUTUAL ORAL STIMULATION OF GENITALS	☐	☐	☐
7. ORAL STIMULATION OF YOUR PARTNER'S GENITALS	☐	☐	☐
8. INTERCOURSE-SIDE BY SIDE	☐	☐	☐
9. KISSING OF SENSITIVE (NON-GENITAL) AREAS OF THE BODY	☐	☐	☐
10. INTERCOURSE-SITTING POSITION	☐	☐	☐
11. MASTURBATING ALONE	☐	☐	☐
12. MALE KISSING FEMALE'S NUDE BREASTS	☐	☐	☐
	YES	NO	PAST 60 DAYS
13. HAVING YOUR ANAL AREA CARESSED	☐	☐	☐
14. BREAST PETTING (CLOTHED)	☐	☐	☐
15. CARESSING YOUR PARTNER'S ANAL AREA	☐	☐	☐
16. INTERCOURSE-FEMALE SUPERIOR POSITION	☐	☐	☐
17. MUTUAL PETTING OF GENITALS TO ORGASM	☐	☐	☐
18. HAVING YOUR GENITALS ORALLY STIMULATED	☐	☐	☐
19. MUTUAL UNDRESSING OF EACH OTHER	☐	☐	☐
20 DEEP KISSING	☐	☐	☐
21. INTERCOURSE-MALE SUPERIOR POSITION	☐	☐	☐
22. ANAL INTERCOURSE	☐	☐	☐
23. KISSING ON THE LIPS	☐	☐	☐
24. BREAST PETTING (NUDE)	☐	☐	☐

SECTION III

Below we would like you to indicate the frequency with which you typically engage in certain sexual activities. Please indicate how often you experience each of the sexual activities below by checking ([✓]) the category that is closest to your personal frequency. Categories range from "NOT AT ALL" to "4 OR MORE TIMES A DAY". Please do not skip any items.

	NOT AT ALL	LESS THAN 1 MONTH	1-2 MONTH	1 WEEK	2-3 WEEK	4-6 WEEK	1 DAY	2-3 DAY	4 OR MORE DAY
1. INTERCOURSE	☐	☐	☐	☐	☐	☐	☐	☐	☐
2. MASTURBATION	☐	☐	☐	☐	☐	☐	☐	☐	☐
3. KISSING AND PETTING	☐	☐	☐	☐	☐	☐	☐	☐	☐
4. SEXUAL FANTASIES	☐	☐	☐	☐	☐	☐	☐	☐	☐

5. WHAT WOULD BE YOUR IDEAL FREQUENCY OF SEXUAL INTERCOURSE ? [ ]

6. AT WHAT AGE DID YOU FIRST BECOME INTERESTED IN SEXUAL ACTIVITY ? [ ]

7. AT WHAT AGE DID YOU FIRST HAVE SEXUAL INTERCOURSE ? [ ]

SECTION IV

Below are a series of statements about various aspects of sexual behavior. We would like to know to what extent you agree or disagree with each one. Please indicate how much you agree or disagree with each statement by placing the appropriate number from the alternatives below in the space alongside the statement. Please do not skip any statements and work quickly.

-2	-1	0	1	2
STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE

1. [ ] PREMARITAL INTERCOURSE IS BENEFICIAL TO LATER MARITAL ADJUSTMENT
2. [ ] HOMOSEXUALITY IS PERVERSE AND UNHEALTHY
3. [ ] SEX IS MORALLY RIGHT ONLY WHEN IT IS INTENDED TO PRODUCE CHILDREN
4. [ ] ORAL SEX CAN BE AS PLEASURABLE AS INTERCOURSE
5. [ ] IT IS UNNATURAL FOR THE FEMALE TO BE THE INITIATOR IN SEXUAL RELATIONS
6. [ ] MASTURBATION IS A PERFECTLY NORMAL, HEALTHY SEXUAL BEHAVIOR
7. [ ] EXTRAMARITAL SEX INEVITABLY LEADS TO SERIOUS PROBLEMS AND GREAT DIFFICULTY IN THE MARRIAGE
8. [ ] WOMEN SHOULD NEVER BE CONSCIOUSLY SEDUCTIVE BUT SHOULD WAIT UPON THE ATTENTIONS OF THE MAN
9. [ ] VIEWING EROTIC FILMS IS ENJOYABLE AND STIMULATING BEHAVIOR
10. [ ] MALES AND FEMALES SHOULD ASSUME BOTH ASSERTIVE AND PASSIVE ROLES DURING INTERCOURSE AND FOREPLAY
11. [ ] MOST HOMOSEXUALS ARE HIGHLY DISTURBED PEOPLE AND A DANGER TO SOCIETY
12. [ ] ANY SEXUAL BEHAVIOR BETWEEN TWO CONSENTING ADULTS SHOULD BE VIEWED AS NORMAL
13. [ ] MORALITY SHOULD NOT BE A CONSIDERATION IN SEXUAL BEHAVIOR
14. [ ] DRESSING IN VARIOUS COSTUMES TO ENHANCE SEXUAL ENJOYMENT SHOULD BE VIEWED AS CREATIVE SEX
15. [ ] BOOKS WHICH CONTAIN PASSAGES EXPLICITLY DESCRIBING SEXUAL ACTS ARE USUALLY JUST TRASH
16. [ ] COUPLES THAT HAVE SEX BEFORE MARRIAGE USUALLY REGRET IT LATER ON
17. [ ] WIFESWAPPING IS ACCEPTABLE IF ALL FOUR PARTNERS AGREE
18. [ ] MALES LOSE RESPECT FOR FEMALES WHO ALLOW THEM TO HAVE PREMARITAL INTERCOURSE
19. [ ] MUTUAL MASTURBATION IN A MARRIED COUPLE IS A POOR SUBSTITUTE FOR INTERCOURSE
20. [ ] PROSTITUTES ARE IMMORAL AND DEGRADING AND HAVE NO PLACE IN SOCIETY
21. [ ] HUMAN GENITALS ARE SOMEWHAT DISGUSTING TO LOOK AT
22. [ ] HOLDING AND TOUCHING MY PARTNER'S BODY IS EXCITING AND THRILLING
23. [ ] GROUP SEX IS A BIZARRE AND DISGUSTING IDEA
24. [ ] EXTRAMARITAL SEXUAL AFFAIRS CAN MAKE PEOPLE BETTER MARITAL PARTNERS
25. [ ] COUPLES SHOULD EXPERIMENT WITH VARIOUS POSITIONS OF INTERCOURSE TO ENHANCE THEIR SEXUAL EXPERIENCES
26. [ ] MASTURBATION FANTASIES ARE HEALTHY FORMS OF SEXUAL RELEASE
27. [ ] HOMOSEXUALITY IS SIMPLY A QUESTION OF SEXUAL ORIENTATION AND NOT GOOD OR BAD, SICK OR HEALTHY
28. [ ] ORAL-GENITAL SEX IS NOT WITHIN THE RANGE OF NORMAL SEXUALITY
29. [ ] A PICTURE OF A NUDE WOMAN CAN BE A BEAUTIFUL AND EXCITING THING TO LOOK AT
30. [ ] PORNOGRAPHY IS PERVERSE AND DISGUSTING IN GENERAL AND PARTICULARLY HARMFUL IN THE HANDS OF YOUNG PEOPLE

SECTION V

Below is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please fill in one of the numbered spaces to the right that best describes HOW MUCH THAT PROBLEM HAS BOTHERED OR DISTRESSED YOU IN THE PAST TWO WEEKS INCLUDING TODAY. *Mark only one numbered space for each problem and do not skip any items.*

HOW MUCH WERE YOU BOTHERED BY :	not at all	slightly	moderately	quite a bit	extremely
1. NERVOUSNESS OR SHAKINESS INSIDE	=0=	=1=	=2=	=3=	=4=
2. FAINTNESS OR DIZZINESS	=0=	=1=	=2=	=3=	=4=
3. THE IDEA THAT SOMEONE ELSE CAN CONTROL YOUR MIND	=0=	=1=	=2=	=3=	=4=
4. FEELING OTHERS ARE TO BLAME FOR MOST OF YOUR TROUBLES	=0=	=1=	=2=	=3=	=4=
5. TROUBLE REMEMBERING THINGS	=0=	=1=	=2=	=3=	=4=
6. FEELING EASILY ANNOYED OR IRRITATED	=0=	=1=	=2=	=3=	=4=
7. PAINS IN HEART OR CHEST	=0=	=1=	=2=	=3=	=4=
8. FEELING AFRAID IN OPEN SPACES	=0=	=1=	=2=	=3=	=4=
9. THOUGHTS OF ENDING YOUR LIFE	=0=	=1=	=2=	=3=	=4=
10. FEELING THAT MOST PEOPLE CANNOT BE TRUSTED	=0=	=1=	=2=	=3=	=4=
11. POOR APPETITE	=0=	=1=	=2=	=3=	=4=
12. SUDDENLY SCARED FOR NO REASON	=0=	=1=	=2=	=3=	=4=
13. TEMPER OUTBURSTS THAT YOU COULD NOT CONTROL	=0=	=1=	=2=	=3=	=4=
14. FEELING LONELY EVEN WHEN YOU ARE WITH PEOPLE	=0=	=1=	=2=	=3=	=4=
15. FEELING BLOCKED IN GETTING THINGS DONE	=0=	=1=	=2=	=3=	=4=
16. FEELING LONELY	=0=	=1=	=2=	=3=	=4=
17. FEELING BLUE	=0=	=1=	=2=	=3=	=4=
18. FEELING NO INTEREST IN THINGS	=0=	=1=	=2=	=3=	=4=
19. FEELING FEARFUL	=0=	=1=	=2=	=3=	=4=
20. YOUR FEELINGS BEING EASILY HURT	=0=	=1=	=2=	=3=	=4=
21. FEELING THAT PEOPLE ARE UNFRIENDLY OR DISLIKE YOU	=0=	=1=	=2=	=3=	=4=
22. FEELING INFERIOR TO OTHERS	=0=	=1=	=2=	=3=	=4=
23. NAUSEA OR UPSET STOMACH	=0=	=1=	=2=	=3=	=4=
24. FEELING THAT YOU ARE WATCHED OR TALKED ABOUT BY OTHERS	=0=	=1=	=2=	=3=	=4=
25. TROUBLE FALLING ASLEEP	=0=	=1=	=2=	=3=	=4=
26. HAVING TO CHECK AND DOUBLE CHECK WHAT YOU DO	=0=	=1=	=2=	=3=	=4=

HOW MUCH WERE YOU BOTHERED BY :	not at all	slightly	moderately	quite a bit	extremely
27. DIFFICULTY MAKING DECISIONS	=0=	=1=	=2=	=3=	=4=
28. FEELING AFRAID TO TRAVEL ON BUSES, SUBWAYS OR TRAINS	=0=	=1=	=2=	=3=	=4=
29. TROUBLE GETTING YOUR BREATH	=0=	=1=	=2=	=3=	=4=
30. HOT OR COLD SPELLS	=0=	=1=	=2=	=3=	=4=
31. HAVING TO AVOID CERTAIN THINGS PLACES OR ACTIVITIES BECAUSE THEY FRIGHTEN YOU	=0=	=1=	=2=	=3=	=4=
32. YOUR MIND GOING BLANK	=0=	=1=	=2=	=3=	=4=
33. NUMBNESS OR TINGLING IN PARTS OF YOUR BODY	=0=	=1=	=2=	=3=	=4=
34. THE IDEA THAT YOU SHOULD BE PUNISHED FOR YOUR SINS	=0=	=1=	=2=	=3=	=4=
35. FEELING HOPELESS ABOUT THE FUTURE	=0=	=1=	=2=	=3=	=4=
36. TROUBLE CONCENTRATING	=0=	=1=	=2=	=3=	=4=
37. FEELING WEAK IN PARTS OF YOUR BODY	=0=	=1=	=2=	=3=	=4=
38. FEELING TENSE OR KEYED UP	=0=	=1=	=2=	=3=	=4=
39. THOUGHTS OF DEATH OR DYING	=0=	=1=	=2=	=3=	=4=
40. HAVING URGES TO BEAT, INJURE OR HARM SOMEONE	=0=	=1=	=2=	=3=	=4=
41. HAVING URGES TO BREAK OR SMASH THINGS	=0=	=1=	=2=	=3=	=4=
42. FEELING VERY SELF CONSCIOUS WITH OTHERS	=0=	=1=	=2=	=3=	=4=
43. FEELING UNEASY IN CROWDS	=0=	=1=	=2=	=3=	=4=
44. NEVER FEELING CLOSE TO ANOTHER PERSON	=0=	=1=	=2=	=3=	=4=
45. SPELLS OF TERROR OR PANIC	=0=	=1=	=2=	=3=	=4=
46. GETTING INTO FREQUENT ARGUMENTS	=0=	=1=	=2=	=3=	=4=
47. FEELING NERVOUS WHEN YOU ARE LEFT ALONE	=0=	=1=	=2=	=3=	=4=
48. OTHERS NOT GIVING YOU PROPER CREDIT FOR YOUR ACHIEVEMENTS	=0=	=1=	=2=	=3=	=4=
49. FEELING SO RESTLESS YOU COULDN'T SIT STILL	=0=	=1=	=2=	=3=	=4=
50. FEELING OF WORTHLESSNESS	=0=	=1=	=2=	=3=	=4=
51. FEELING PEOPLE WILL TAKE ADVANTAGE OF YOU IF YOU LET THEM	=0=	=1=	=2=	=3=	=4=
52. FEELINGS OF GUILT	=0=	=1=	=2=	=3=	=4=
53. THE IDEA THAT SOMETHING IS WRONG WITH YOUR MIND	=0=	=1=	=2=	=3=	=4=

SECTION VI

Below is a list of words that describe the way people sometimes feel. We would like you to tell us whether you have been having any of these feelings during the past TWO WEEKS. *Please indicate the degree to which you have typically felt each emotion by filling in one of the numbered spaces that best describes your experience.*

	never	rarely	sometimes	frequently	always		never	rarely	sometimes	frequently	always
1. NERVOUS	=0=	=1=	=2=	=3=	=4=	21. CHEERFUL	=0=	=1=	=2=	=3=	=4=
2. SAD	=0=	=1=	=2=	=3=	=4=	22. SATISFIED	=0=	=1=	=2=	=3=	=4=
3. REGRETFUL	=0=	=1=	=2=	=3=	=4=	23. ACTIVE	=0=	=1=	=2=	=3=	=4=
4. IRRITABLE	=0=	=1=	=2=	=3=	=4=	24. FRIENDLY	=0=	=1=	=2=	=3=	=4=
5. HAPPY	=0=	=1=	=2=	=3=	=4=	25. ANXIOUS	=0=	=1=	=2=	=3=	=4=
6. PLEASED	=0=	=1=	=2=	=3=	=4=	26. MISERABLE	=0=	=1=	=2=	=3=	=4=
7. EXCITED	=0=	=1=	=2=	=3=	=4=	27. GUILTY	=0=	=1=	=2=	=3=	=4=
8. PASSIONATE	=0=	=1=	=2=	=3=	=4=	28. ENRAGED	=0=	=1=	=2=	=3=	=4=
9. TIMID	=0=	=1=	=2=	=3=	=4=	29. DELIGHTED	=0=	=1=	=2=	=3=	=4=
10. HOPELESS	=0=	=1=	=2=	=3=	=4=	30. RELAXED	=0=	=1=	=2=	=3=	=4=
11. BLAMEWORTHY	=0=	=1=	=2=	=3=	=4=	31. VIGOROUS	=0=	=1=	=2=	=3=	=4=
12. RESENTFUL	=0=	=1=	=2=	=3=	=4=	32. AFFECTIONATE	=0=	=1=	=2=	=3=	=4=
13. GLAD	=0=	=1=	=2=	=3=	=4=	33. AFRAID	=0=	=1=	=2=	=3=	=4=
14. CALM	=0=	=1=	=2=	=3=	=4=	34. UNHAPPY	=0=	=1=	=2=	=3=	=4=
15. ENERGETIC	=0=	=1=	=2=	=3=	=4=	35. REMORSEFUL	=0=	=1=	=2=	=3=	=4=
16. LOVING	=0=	=1=	=2=	=3=	=4=	36. BITTER	=0=	=1=	=2=	=3=	=4=
17. TENSE	=0=	=1=	=2=	=3=	=4=	37. JOYOUS	=0=	=1=	=2=	=3=	=4=
18. WORTHLESS	=0=	=1=	=2=	=3=	=4=	38. CONTENTED	=0=	=1=	=2=	=3=	=4=
19. ASHAMED	=0=	=1=	=2=	=3=	=4=	39. LIVELY	=0=	=1=	=2=	=3=	=4=
20. ANGRY	=0=	=1=	=2=	=3=	=4=	40. WARM	=0=	=1=	=2=	=3=	=4=

SECTION VII

Below is a list of personality characteristics that are often used to describe people. We would like you to describe yourself in terms of these characteristics. To do this, please indicate the degree to which each trait is typical of you--in other words, how much of each characteristic you have. Use the numbered scale given below, and place the appropriate number alongside each trait.

0	1	2	3	4
NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY

1. SYMPATHETIC [ ]
2. DECISIVE [ ]
3. FRIVOLOUS [ ]
4. PRACTICAL [ ]
5. SENTIMENTAL [ ]
6. RATIONAL [ ]
7. SECRETIVE [ ]
8. CONFIDENT [ ]
9. COMPASSIONATE [ ]
10. VIGOROUS [ ]
11. SENSITIVE [ ]
12. INDEPENDENT [ ]
13. DOMESTIC [ ]
14. BOLD [ ]
15. DEPENDENT [ ]
16. ADVENTUROUS [ ]
17. FELINE [ ]
18. STRONG [ ]
19. FLIRTATIOUS [ ]
20. MECHANICAL [ ]
21. GRACEFUL [ ]
22. DOMINANT [ ]
23. SEDUCTIVE [ ]
24. AUTHORITATIVE [ ]
25. WHIMSICAL [ ]
26. ATHLETIC [ ]
27. FASHIONABLE [ ]
28. AGGRESSIVE [ ]
29. GENTLE [ ]
30. ASSERTIVE [ ]

SECTION VIII

In this section we have listed a variety of sexual ideas, and fantasies that people sometimes have. We would like you to indicate which of these fantasies you have experienced either in daydreams or dreams while asleep. For each fantasy that you have experienced place a check ({✓} in the space alongside that item.

1. { } HAVING MORE THAN ONE SEXUAL PARTNER AT THE SAME TIME
2. { } HAVING INTERCOURSE IN UNUSUAL POSITIONS
3. { } HAVING SEXUAL RELATIONS WITH ANIMALS
4. { } WHIPPING OR BEATING YOUR SEXUAL PARTNER
5. { } FORCING A PARTNER TO SUBMIT TO SEXUAL ACTS
6. { } DRESSING IN CLOTHES OF THE OPPOSITE SEX
7. { } USING ARTIFICIAL DEVICES FOR SEXUAL STIMULATION
8. { } BEING A PROSTITUTE
9. { } FORBIDDEN LOVER OR MISTRESS IN SEXUAL ADVENTURES
10. { } HOMOSEXUAL FANTASIES
11. { } MATESWAPPING FANTASIES
12. { } BEING TIED UP OR BOUND DURING SEXUAL ACTIVITIES
13. { } DEGRADING A SEX PARTNER
14. { } BEING SEXUALLY DEGRADED
15. { } ANAL INTERCOURSE
16. { } DRESSING IN EROTIC GARMENTS
17. { } SEXUAL INTERCOURSE
18. { } FANTASIZING THAT YOU ARE OF THE OPPOSITE SEX
19. { } ORAL-GENITAL SEX
20. { } BEING FORCED TO SUBMIT TO SEXUAL ACTS

SECTION IX

Below are some statements concerning how you view your body. Please indicate to what degree each of the following statements is <u>*true of you*</u> *by circling the number that best describes your experience. Note that Part A is for both sexes, Part B is for men only, and Part C is for women only.*

	PART A (BOTH SEXES)	not at all ▼	slightly ▽	moderately ▼	quite a bit ▽	extremely ▼
1.	I AM LESS ATTRACTIVE THAN I WOULD LIKE TO BE	0	1	2	3	4
2.	I AM TOO FAT	0	1	2	3	4
3.	I ENJOY BEING SEEN IN A BATHING SUIT	0	1	2	3	4
4.	I AM TOO THIN	0	1	2	3	4
5.	I WOULD BE EMBARASSED TO BE SEEN NUDE BY A LOVER	0	1	2	3	4
6.	I AM TOO SHORT	0	1	2	3	4
7.	THERE ARE PARTS OF MY BODY I DON'T LIKE AT ALL	0	1	2	3	4
8.	I AM TOO TALL	0	1	2	3	4
9.	I HAVE TOO MUCH BODY HAIR	0	1	2	3	4
10.	MY FACE IS ATTRACTIVE	0	1	2	3	4

PART B (MEN ONLY)

		not at all	slightly	moderately	quite a bit	extremely
11.	I HAVE A WELL PROPORTIONED BODY	0	1	2	3	4
12.	I AM SATISFIED WITH THE SIZE OF MY PENIS	0	1	2	3	4
13.	WOMEN WOULD FIND MY BODY ATTRACTIVE	0	1	2	3	4
14.	I AM WELL-COORDINATED AND ATHLETIC	0	1	2	3	4
15.	I AM PLEASED WITH THE PHYSICAL CONDITION OF MY BODY	0	1	2	3	4

PART C (WOMEN ONLY)

		not at all	slightly	moderately	quite a bit	extremely
16.	I HAVE A SHAPELY AND WELL PROPORTIONED BODY	0	1	2	3	4
17.	I HAVE ATTRACTIVE BREASTS	0	1	2	3	4
18.	MEN WOULD FIND MY BODY ATTRACTIVE	0	1	2	3	4
19.	I HAVE ATTRACTIVE LEGS	0	1	2	3	4
20.	I AM PLEASED WITH THE WAY MY VAGINA LOOKS	0	1	2	3	4

SECTION X

Below are some statements about sexual satisfaction. Please indicate whether each statement is true of you by checking either true or false for each item.

		TRUE	*FALSE*
1.	USUALLY, I AM SATISFIED WITH MY SEXUAL PARTNER	T	F
2.	I FEEL I DO NOT HAVE SEX FREQUENTLY ENOUGH	T	F
3.	THERE IS NOT ENOUGH VARIETY IN MY SEX LIFE	T	F
4.	USUALLY AFTER SEX I FEEL RELAXED AND FULFILLED	T	F
5.	USUALLY, SEX DOES NOT LAST LONG ENOUGH	T	F
6.	I AM NOT VERY INTERESTED IN SEX	T	F
7.	USUALLY, I HAVE A SATISFYING ORGASM WITH SEX	T	F
8.	FOREPLAY BEFORE INTERCOURSE IS USUALLY VERY AROUSING FOR ME	T	F
9.	OFTEN, I WORRY ABOUT MY SEXUAL PERFORMANCE	T	F
10.	USUALLY, MY PARTNER AND I HAVE GOOD COMMUNICATION ABOUT SEX	T	F

GSSI - Below is a rating scale upon which we would like you to record your personal evaluation of how satisfying your sexual relationship is. The rating is simple. Make your evaluation by placing a check in the appropriate box that best describes your present sexual relationship.

{ } 8 COULD NOT BE BETTER
{ } 7 EXCELLENT
{ } 6 GOOD
{ } 5 ABOVE AVERAGE
{ } 4 ADEQUATE
{ } 3 SOMEWHAT INADEQUATE
{ } 2 POOR
{ } 1 HIGHLY INADEQUATE
{ } 0 COULD NOT BE WORSE

APPENDIX C

MEMORIAL HOSPITAL
1275 YORK AVENUE
NEW YORK, N.Y. 10021

PATIENT INVESTIGATIVE CONSENT FORM

CONSENT FOR NEW PROCEDURE, STUDY OR DRUG UNDER CLINICAL INVESTIGATION

PATIENT

I have been asked to participate in a study of psychological adjustment to the successful treatment of Hodgkin's disease. The chief investigator of this project is Jimmie C.B. Holland, M.D., a Memorial Hospital attending physician.

Participation in this study will entail approximately two hours of my time and will be scheduled at my convenience. I will be interviewed briefly, then asked to complete five short questionnaires, followed by an exercise in which I will tell imaginative stories to some pictures. A member of the study staff will be with me the entire time, and answer any questions I might have. This person, David Cella, can be reached for further questioning at (212) 794-8229. If I don't call him, he will phone me within the next month as a routine follow-up.

I understand that participation in this study is voluntary, and that I will receive no direct benefit by participating. I know that I can withdraw from the study at any time, and that my medical treatment will in no way be influenced by such a decision. I also know that, short of withdrawing from the project, I may decide not to answer any question or set of questions, and still continue with the interview.

I have been informed that the study will involve questions about personal sexual matters, death-related concerns, self esteem, uncertainty, anxiety, and stress. All information I disclose to the study investigator will be kept in the strictest confidence and used only for research purposes. My name will not appear on any document or publication which might emerge from this project.

While there are no physical risks involved in my taking part in this study, a few of the questions might revive emotional experiences which may at one time have been distressing. However, the interviewer will be available to discuss this with me should it occur.

With the above in mind, I, ______________________, agree to participate in the study described above. It has been explained to my satisfaction, and I have been given the opportunity to discuss it further.

SIGNED: ______________________ DATE: ______________________

I have fully explained to the participant the nature and purpose of the study described above.

____
Signature of research staffperson

MEMORIAL HOSPITAL
1275 YORK AVENUE
NEW YORK, N.Y. 10021

PATIENT INVESTIGATIVE CONSENT FORM

CONSENT FOR NEW PROCEDURE, STUDY OR DRUG UNDER CLINICAL INVESTIGATION

C

CONTROL

I have been asked to participate, as a member of a comparison group, in a study of the successful treatment of Hodgkin's disease. The chief investigator of this project is Jimmie C.B. Holland, M.D., a Memorial Hospital attending physician.

Participation in this study will entail approximately two hours of my time, and will be scheduled at my convenience. I will be interviewed briefly, then asked to complete five short questionnaires, followed by an exercise in which I will tell imaginative stories to some pictures. A member of the study staff will be with me the entire time to answer any questions I might have. This person, David Cella, can be reached for further questioning at (212) 794-8229. If I don't call him, he will phone me within the next month as a routine follow-up.

I understand that participation in this study is voluntary, and that I will receive no direct benefit by participating. I know that I can withdraw from the study at any time. I also know that, short of withdrawing from the project, I may decide not to answer any question or set of questions, and still continue with the interview.

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With the above in mind, I, ________________________, agree to participate in the study described above. It has been explained to my satisfaction, and I have been given the opportunity to discuss it further.

SIGNED: ____________________________ DATE: ____________________

I have fully explained to the participant the nature and purpose of the study described above.

____

Signature of research staffperson

APPROVAL SHEET

The dissertation submitted by David F. Cella has been read and approved by the following committee:

Dr. Patricia A. Rupert, Director
Assistant Professor, Psychology, Loyola

Dr. Dan P. McAdams
Assistant Professor, Psychology, Loyola

Dr. Alan S. DeWolfe
Professor, Psychology, Loyola

The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

October 5, 1983
Date

Patricia A. Rupert
Director's Signature