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IMPACT OF VIEWING AN EDUCATIONAL VIDEOTAPE PROGRAM ON THE SIGNIFICANT OTHERS OF RADIATION THERAPY ONCOLOGY PATIENTS

A Dissertation Presented

by

HELEN MORGAN BEATTIE

Submitted to the Graduate School of the
University of Massachusetts in partial fulfillment
of the requirements for the degree of

DOCTOR OF EDUCATION

May, 1989

School of Education

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ABSTRACT

IMPACT OF VIEWING AN EDUCATIONAL VIDEOTAPE PROGRAM ON THE SIGNIFICANT OTHERS OF RADIATION THERAPY ONCOLOGY PATIENTS

MAY, 1989

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The significant others of cancer patients are assuming an increasing degree of responsibility for the care of their loved ones. Given this shift in responsibility from hospital to home, the health care system is not adequately responsive to the increased information and support needs of patients' significant others.

The purpose of this study was to evaluate the impact of two educational interventions on the knowledge level regarding radiation therapy, and on the emotional dispositions of the significant others who accompanied cancer patients to outpatient radiation therapy. This research is the first controlled study designed to document the usefulness of employing an education videotape to meet the needs of this population.

Twenty-nine individuals who accompanied their family member or friend to a radiation therapy clinic were randomized to either a Usual Treatment (n=15) or a Videotape Treatment (n=14) group. The Usual subjects received the educational and counseling services generally offered to all patients and family members. In addition to these services, the Videotape subjects saw a video program designed to provide information and address emotional needs. Outcome measures included pre- and post-test ratings of each subject's understanding of radiation therapy and a questionnaire designed to assess mental health status. Videotape Treatment subjects also completed a subjective written assessment about the videotape. Additionally, approximately one-half of subjects in each intervention group took part in a semi-structured interview regarding their clinic experience.

Comparison of knowledge post-test performances of these two groups revealed that Videotape subjects knew significantly more about radiation therapy than did Usual subjects ($p<.0005$). The groups did not differ in their mental health status at either testing session.

Videotape subjects consistently expressed satisfaction with the content and format of the film in both written assessments and in interviews. The majority of individuals who saw the video reported that it facilitated communication with doctors and nurses. They also noted that the videotape provided helpful, readily understood information which served to lessen their fears and offered optimism about the future.

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CHAPTER 1

INTRODUCTION

The Problem

The present health care system does not adequately meet the informational and psychosocial needs of individuals with chronic illness or of their significant others (Dodd, 1982; Jamison, Wellisch and Pasnau, 1978; Korsch, Gozzi and Francis, 1968). Drastic changes presently occurring in the health care realm are intensifying this problem. Patients are now released from the hospital after the shortest possible stay, often with complex and demanding medical and nursing needs. Procedures and courses of treatment previously done on an inpatient basis are being shifted to the outpatient department or home care services. Concurrent staffing cutbacks make it difficult and at times impossible for professionals to adequately assess or respond to the questions, concerns and educational needs of patients and their significant others prior to discharge or in the outpatient setting.

Trends in the Health Care System

Efforts to curb rapidly escalating expenditures have resulted in major changes in insurance reimbursement and health care delivery. Tremendous turmoil is now apparent in the health care system. The cost of medical care consumed over ten percent of the Gross National Product in 1984 and has increased at an annual rate far above that of general inflation (Coleman and Dayani, 1984). Governmental subsidy of health programs has decreased. Competition has been advocated as a primary vehicle by which to contain costs.

Central to changes now occurring has been a shift in how the third party payers reimburse for hospital services. Insurance reimbursement is changing from a retrospective system, where the physician or hospital is paid for actual services rendered, to a prospective reimbursement system. Prospective reimbursement means that an insurance company or state or federal agency makes a decision that there is an average cost for any given disease or medical problem. This is commonly called a Diagnosis Related Group (D.R.G.) system. This then becomes the flat rate reimbursed to the treating institution.

This system prompts hospitals to seek means to reduce the cost of patient care, thereby profiting from the difference between actual costs of care and the higher amount reimbursed by the D.R.G.s. Retrospective reimbursement rewarded hospitals and physicians for longer lengths of stay and more laboratory testing and procedures by paying for all services provided. Under the present system, excessive testing, unnecessary admissions or prolonged lengths of stay are not reimbursable by third parties and become a debt factor to the institution and/or physician. This dramatic change in insurance coverage is literally revolutionizing the nature of the delivery of medical care in the hospital setting.

Another major force in the changing profile of health care is the development of alternative models of medical care delivery, namely the advent of Health Maintenance Organizations (H.M.O.s), Individual Practice Associations (I.P.A.s) and Preferred Provider Organizations (P.P.O.s). These alternative forms of providing health care services aggressively seek methods to reduce costs through many strategies, but primarily by minimizing hospitalizations. Careful review of many of these plans reveals decreased coverage for necessary out-of-hospital medical care for chronically ill patients, for example the coverage of home care services. These enterprises make money on well-patient care and lose money on that segment of their enrollees having serious, long-term diseases. They therefore do not cater to these individuals, often creating great logistical and psychological hardships for that cohort of patients deemed to **not** be cost effective.

A major clinical consequence of the new cost-oriented system is that of increasingly shorter lengths of stay for inpatients and greater utilization of ambulatory care facilities. Routine modified radical mastectomies and cardiac catheterizations in some institutions are now one-day ambulatory procedures. Patients are being discharged after increasingly shorter lengths of stay in a more acutely ill state. Friends and family members are expected to provide the level of medical and nursing care previously delivered in the hospital. This role is often assumed with little preparation from medical and nursing personnel prior to discharge.

Given the difficulties inherent in the situation described above, why isn't the system responding to the educational needs of patients and their significant others? Educational efforts are not revenue generating. Third party payers generally do not offer reimbursement for time spent preparing the patient and family or involved friends to deal with their far-reaching range of needs and concerns. Staffing cutbacks are being witnessed as institutions now fight for their financial viability. "The demands of the work of physicians, nurses, and other medical specialists usually leave them insufficient time in which to adequately provide patient education" (O'Connor, 1982, p.5). Given the reality of rising acuity levels at time of discharge and an increasing frequency of outpatient procedures, the lack of clinical and psychological preparation of clients and their significant others is becoming a pervasive problem within the health care system.

Implications for the Patient's Significant Others

The term "significant other" is defined as any individual who is emotionally invested in the well-being of the patient and who is not merely an acquaintance. This may be a spouse, partner, child, relative or friend. The majority of studies assessing the impact of a chronic disease diagnosis on the significant others of patients has been restricted to the patient's partner and immediate family. It is clear that these individuals must personally cope with a threat to multiple aspects of their psychological, social and physical stability. Although lacking empirical documentation, friends and relatives who are also emotionally invested in the well-being of the patient are likely to be similarly impacted by the cancer diagnosis. The basic needs of the network of significant others of cancer patients will now be briefly reviewed to bring to light the depth and range of their concerns, keeping in mind that the system is increasingly less able to help these individuals.

A substantial body of literature documents the profound impact illness can have on the family of a seriously ill patient. "Strong reactions of fear, anger, uncertainty and helplessness are not confined to the individual with cancer but extend to family members and significant others who are involved with that individual's life" (Tringali, 1986, p.65). Anthony

(1970) studied the effect of mental and physical illness on family life and observed that "to some extent, the family is always sick along with the sick member, sometimes physically, sometimes psychologically and often empathetically" (p.141). Lewis (1983) researched the effect of the cancer diagnosis on the family. He notes, "the process of family realizations is not a linear process with simple increments and gradual positive evolution. It is best described as a turbulent psychosocial transition" (p.194).

What are the issues which the patient's significant other(s) must confront? Role responsibilities often shift to the well partner or family member to accommodate limited abilities of the patient (Bruhn, 1977; Northouse, 1984). This frequently places a tremendous burden upon this individual. Northouse (1984) notes that the family also faces the problem of "finding a balance in time that they devote to the member with cancer and the time they devote to the growth needs of other family members" (p.226) due to these role changes.

Psychologically, the patient's significant others must fight to maintain a sense of control. The waiting process, a seemingly unavoidable aspect of chronic medical care, is one factor which threatens their perceived ability to manage their lives (Barckley, 1967; Welch, 1981). The increase of procedures and treatments administered on an outpatient basis will serve to increase the frequency of the days and weeks in which patients and their family and friends try to control heightened tension due to anticipation of real or imagined potential physical and emotional distress. During this time, access to information can be difficult at best, imposing a sense of dependence, vulnerability and a heightened fear of the unknown (Jensen, 1985; Molter, 1979; Northouse, 1984; Tringali, 1986; Wright and Dyck, 1984).

An acute sense of helplessness is often felt by individuals caring for a chronically ill person (Cassileth and Hamilton, 1979; Koocher, 1979). It is a reality that the patient's caretaker, regardless of how well he tends to the needs of his loved one, is unable to impact on the existence of the disease itself. Lack of education on how to adequately care for the patient who now is discharged in a more acutely ill state than ever before may serve to further diminish the caretaker's sense of competency. This intensifies the struggle of the patient's significant other to maintain a semblance of control or confidence in his or her ability to manage.

The disequilibrium prompted by a chronic disease diagnosis is often accompanied by a questioning of life's meaning and purpose (Mechanic, 1977). The patient's significant others can be confronted with a threat to their most basic needs for intimacy, stability and security and are reminded of their own mortality (Giacquinta, 1977; Northouse, 1984; Skelton and Dominian, 1973). Future plans often must be put on hold. Feelings of fear, anger and sadness are emotions experienced by significant others in the process of grieving for their previous relationship with the patient, which of necessity must often endure substantial change to survive (Corbin and Strauss, 1984).

The literature reveals that the expression of intimacy between partners is another life dimension which can be greatly altered by both the physical and psychological realities of illness (Dyk and Sutherland, 1956; Katz, 1969; Leiber, Plumb, Gerstenzang and Holland, 1976). It has been suggested that spouses can experience greater dissatisfaction with the changes in their intimate physical relationship than do patients (Leiber et al., 1976).

The social network of the family of a cancer patient often changes as a result of the demands of coping with the diagnosis (Giacquinta, 1977; Thorne, 1985). "The extrafamilial effects of illness may lead to the family's withdrawal from active contact with the outside world so that friendships and affiliations are gradually discarded" (Anthony, 1970, p.57). New found financial concerns and responsibilities can be a factor influencing these social changes (Cassileth and Hamilton, 1979; Molter, 1979; Welch, 1981). Ironically, the shrinking of the existing social network occurs at a time when the family has the greatest need for emotional and logistical support.

Finally, the stress imposed on the family has been shown to manifest itself in psychosomatic symptoms (i.e. headaches, sleeping problems, et cetera). This has been documented in the partners of patients and is noticeably present during the diagnosis and immediate post-diagnosis phases of illness (Cooper, 1984; Dyk and Sutherland, 1956; Klein, Dean and Bogdonoff, 1967).

Evidence indicates that the ways in which the patient's network of significant others respond to the illness can impact on the course of the patient's disease. It has been suggested that there is a cause and effect relationship between the patient's physical recovery and family functioning (Steidl et al., 1980). Cassileth et al. (1985) conducted a psychological analysis of cancer patients and their next-of-kin to study the relationship. They found a significant correlation between the anxiety, mood disturbance and mental health state of the patient when compared to their next-of-kin. They concluded that "supportive intervention for the patient or relative who manifests distress, therefore, should benefit both" (Cassileth, 1985, p.72).

Despite the known needs of the significant others of patients and their pivotal role within the rehabilitation process, they are afforded minimal attention within the medical system. In fact, this system appears increasingly less responsive to the educational needs of both the patient and their loved ones. All too often the system reacts only to obvious crises rather than proactively educating and supporting the patient and their significant others to facilitate coping with a major life change. "The time to promote collaborative work patterns between spouses and with the health care team is not when the couple is having coordinating difficulties but at the time of the diagnosis of chronic illness" (Corbin and Strauss, 1984, p.115).

Implications for the Significant Others of Radiation Therapy Patients

Over 50 percent of all cancer patients will undergo radiation therapy at some point during the course of their illness (Dudjak, 1987). There is reason to believe that the educational and emotional needs of the significant other(s) of individuals undergoing radiation therapy for a recent cancer diagnosis is great.

What evidence exists to indicate that this is a needy population? The available literature on the emotional reactions of **patients** undergoing radiation therapy (Forester, Kornfeld and Fleiss, 1978; Holland, Rowland, Lebovits and Rusalem, 1979; Kubricht, 1984; Mitchell and Glicksman, 1977) reveals that for them, it is a time fraught with high anxiety. These studies generally concur with the following findings of Peck and Boland (1977), "Patients suffer irrational fears of damage and death because of erroneous preconceptions of radiation" (p.180). Dudjak (1987) concurs, "In spite of its wide application, radiation therapy continues to be associated with a host of fears, misconceptions and misinformation regarding the treatment experience, side effects, potential for hazard to others and even implications for prognosis" (p.45). Although study of this group is limited, it is fair to assume that the friends and family members of patients also share these fears and anxieties. In fact, Welch (1981) suggests that families may have a more difficult time psychologically adjusting to illness, "in part related to having second hand knowledge throughout the patient's hospitalization" (p.366).

Bond (1982) studied the communication needs of 108 next-of-kin of cancer patients who were receiving **radical radiotherapy treatment** in a hospital in England. This type of treatment required a minimum of five days of hospitalization. All subjects completed questionnaires regarding their communication patterns with the hospital staff. Additionally, 30 spouses from this subject base were interviewed. She found that relatives wanted to know more about "'Why is this treatment necessary?' 'Is this treatment doing any good?' and, 'A clearer explanation of the condition and the side-effects of treatment and how to help the patient more at home'" (p.965). Bond did discover ambivalence on the part of next-of-kin in their information seeking behavior. "It is evident that relatives could have been living with misapprehensions about the illness which factual information would have clarified, and in fact, present a more optimistic picture than that held. On the other hand relatives were not prepared to have their hopes dashed" (p.964).

Only one study has begun to research the specific needs of the family members of cancer patients undergoing **out-patient radiation therapy**. Tringali (1986) drew a small convenience sample of 25 subjects from **both** the medical and radiation therapy outpatient units of a hospital for her study. These individuals completed 53 need statements using a Likert-type scale. She found that the most important needs of family members were information about "the disease, the treatment, when to expect symptoms to occur, and to be told facts about the patient's progress and the probable outcome of the patient's condition". She concluded that assisting family members to obtain this information "prepares family members for supportive tasks such as reinforcement of the treatment goals, reality-based encouragement, treatment of side effects and clarification of information delivered but perhaps not retained by the patient due to anxiety" (p.69). As important as being able to support the patient, Tringali notes that this information helps to reduce the family members' anxiety and increase their sense of control.

Educational interventions need to be developed, tested, and made available to patients and family members going through radiation therapy. The medical system must begin to fill a critical gap in the delivery of health care services through the development of sound educational and support programs. This effort must be solidly based on research designed to discern alternative means to meet the educational needs of patients and their significant others; individuals who involuntarily find themselves dependent upon a complex and often contradictory health care system.

Purpose of the Study

The purpose of the study was to evaluate the impact of two educational interventions on the knowledge levels regarding radiation therapy and state of emotional dispositions of the significant others who accompanied cancer patients to outpatient radiation therapy at the University of Massachusetts Medical Center. More specifically, the impact of significant others viewing an educational videotape in addition to the usual staff educational efforts was assessed.

Presently, no educational intervention exists solely for the significant other who accompanies the cancer patient to radiation treatment at the University of Massachusetts Medical Center. From a review of the literature, this apparently is not an uncommon situation. There is no evidence to suggest that any educational or counseling interventions for significant others are commonly initiated in other radiation therapy clinics.

This experimental design study began to seek answers to the following questions: Does viewing of a videotape have the potential to impart knowledge to the significant other who accompanies the patient to treatment? Does use of the videotape as a teaching tool have the ability to improve the viewer's emotional disposition?

The results of this study will be used to develop an "educational protocol" for significant others at the University of Massachusetts Medical Center radiation therapy clinic. It may be useful for other radiation therapy clinics interested in developing educational programs for this population. Additionally, it will serve as a foundation for further research in this area.

Significance

Videotapes have come to be appreciated as a useful and powerful vehicle by which to deliver needed information to patients and family members. They appear to be a cost effective means of providing education, minimizing the time needed by staff to deliver this information over and over again (Bakker, 1987; Hecht, 1980; Williams and Manske, 1987). Theoretically, by incorporating videotapes into their educational efforts, nurses, physicians and other health professionals can better utilize their time with the patient and the patient's significant other(s) by responding to their unique needs and concerns.

Despite a seemingly widespread belief in the effectiveness of videotapes as an educational tool, there has been limited research to assess their use as a vehicle to educate individuals involved in the health care system. A number of studies have found that videotapes were effective in increasing patients' knowledge of their disease or the procedure or treatment they were to undergo (Bakker, 1987; Black and Mitchell, 1977; Israel and Mood, 1982; Lawson, Traylor and Gram, 1976; Melamed and Siegel, 1975; Moldofsky, Broder, Davis and Leznoff, 1979; Padilla, Grant, Rains and Hansen, 1981; Shipley, Butt, Horowitz and Farbry, 1978; Vernon, 1973; Williams and Manske, 1987). Only one study, Cassileth et al., 1982, has attempted to evaluate the potential usefulness of videotapes as an educational tool for the "next-of-kin" of cancer patients, demonstrating that they were effective in increasing knowledge and decreasing anxiety in this subject population (see page 60 for details on this study).

Further research is needed to contribute to an understanding of the potential usefulness of videotapes as a vehicle to address some of the educational and emotional needs of the patient's significant other(s). This research, along with the Cassileth et al. (1982) study, will comprise the available body of knowledge in this area.

Summary

The increasing incidence of outpatient procedures and treatments and a trend toward early discharges is paralleled by a decrease in the health care system's ability to provide adequate education for patients and family members. It is imperative that the patient's significant other(s), who will be primarily responsible for care of the individual at home, be educated to assume this responsibility.

Cassileth et al. (1985) found that because of the interrelationship between the mental state of patients and their "next-of-kin", "supportive intervention for the patient or relative who manifests distress, therefore, should benefit both" (p.72). By better addressing the information and emotional needs of the patient's significant other, it may well be possible to enhance the recovery process of the patient. A number of studies suggest that the incorporation of videotapes into existing education efforts is a means to this end.

This study targets the radiation therapy population but has broader implications for the education of significant others coping with a range of illnesses. This is a research field ripe for exploration which has the potential to have a significant positive impact on the method of education utilized within the health care realm.

CHAPTER 2

LITERATURE REVIEW

This literature review will be presented in three sections. In the first section, the needs of the significant other of cancer patients in the immediate post-diagnosis phase will be reviewed.

The second section will explore the known psychological reactions of individuals undergoing radiation therapy and of their significant others, indicating the need for better educational interventions to lessen the fear and anxiety associated with this method of treatment.

The third section of the literature review will begin with a description of studies relative to the effectiveness of utilizing audiovisuals for patient and family education. Empirical research focused specifically on the assessment of the impact of using videotapes will then be reviewed in depth. Special attention will be directed to those few studies which provide a foundation for the present study, highlighting how the author's research promises to enhance the present limited knowledge base in this area.

Section One:

The Response of a Cancer Patient's Significant Other to Illness

The needs of the significant others of cancer patients has been briefly reviewed in Chapter One. This topic will now be explored in greater depth by means of a more thorough review of the literature.

Empirical research regarding the response of families to chronic illness is scarce. Lewis (1983) notes, "to date there has been limited consideration of family level measurements in the cancer nursing literature and Litman (1979) has argued that family level research (regardless of discipline) has suffered from severe methodological constraints" (p.379). The literature relating specifically to the needs and concerns of significant others outside of the immediate family structure is predictably yet more scarce.

The research that specifically relates to the needs and concerns of the significant others of **cancer patients** is the focus of this section. As will become evident, this area of study is very limited and warrants further development. Where appropriate, broader studies which describe the process of how families cope with chronic disease will be cited to supplement the review.

The psychological, social and physical ramifications of being the significant other of an individual who is newly diagnosed with cancer will now be systematically explored.

Psychological Adaptation

"When cancer is diagnosed, the family faces not only the immediate threat of crisis, but also the expectation of chronic, enduring changes in its patterned roles, relationships, and sense of unit self" (Cassileth and Hamilton, 1979, p.233). The cancer diagnosis throws the patient and each person within the family into a state of crisis. Individually and collectively, family members struggle to realize the impact of a life-threatening disease on their loved one, on themselves, and on the family unit. Wellisch (1978) quotes the wife of a cancer patient who stated, "'Cancer is like another member of our family, an unwelcome member'" (p.228).

Cohen and Wellisch (1978) describe the state induced on a family by the cancer diagnosis as "living in limbo". They suggest that, "Cancer is not so much a separate problem in family process as it is an accent upon the usual mode of functioning" (p.562). Likewise, Fife (1985) notes, "The onset of a serious illness is a particularly dramatic crisis that magnifies the dynamics of ordinary family interaction and accentuates any problems that already exist" (p.108). Litman (1974), a medical sociologist, observed that there exists an equal chance that family members will be brought closer together as driven further apart due to the member's medical condition (p.509).

Northouse (1984) conducted a comprehensive literature review regarding the impact of cancer on the family. She notes that the "diagnosis of cancer, with its life-threatening connotations, generates considerable anxiety within a family. This anxiety can be contagious, spreading from one family member to another and creating emotional strain and tension within and among the individuals" (p.223). Bruhn (1977) observed that, "Chronic illness especially disrupts the usual way in which family members behave toward one another and then hampers their ability to overcome the effects of this disruption" (p.1057).

Adaptation of the spouse and other family members to a colostomy was studied by Dyk and Sutherland (1956). They noted that, "Illness in a husband or wife does not automatically call forth the best efforts in the spouse. Rather it is a serious threat in the dynamic equilibrium of the relationship" (p.137), and may lead to heightened conflict and loss of intimacy. They further suggest that "the spouse is often the key to the patient's success or failure in adapting himself to his disability" (p.138). "No matter how much they love the patient, most family members are bound to resent the enormous responsibility thrust upon them and the changes the ill person has brought about in their lives" (Wortman and Dunkel-Schetter, 1979, p.140). Some relationships will grow stronger through this adversity while others will deteriorate.

As mentioned briefly in Chapter 1, Cassileth et al. (1985) documented a close correlation between the psychological status of the patient with that of their next-of-kin. Self-report tests of anxiety, mood disturbance and mental health were delivered to 201 cancer patients and their next-of-kin. Results revealed a close correlation in psychological status between the patient and their matched next-of-kin suggesting a tandem emotional response to serious illness. The study infers that "supportive intervention for the patient or relative who manifests distress, therefore, should benefit both" (p.72). Attending to the needs of the next-of-kin has also been shown to influence the patient's stress level (Cronkite and Moos, 1984) as well as their compliance with medical treatment (Steidl et al., 1980).

The crisis of a cancer diagnosis seriously challenges a marital or next-of-kin relationship. Prediction of the course of adaptation a family or relationship with a significant other will take remains difficult, however, several key factors appear to underlay the psychological adjustment of the significant others of a cancer patient. The literature suggests that the significant others face three major psychological hurdles:

1. Maintain a sense of control
2. Reestablish a sense of purpose and meaning
3. Redefine the nature of intimacy shared with the partner

Sense of Control

The control felt by the significant other of a newly diagnosed cancer patient is impinged upon in three primary ways. The waiting process, an inevitable element of chronic medical care, has come to be seen as a major factor which robs individuals of their ability to manage. Secondly, access to information can be difficult at best, imposing a sense of dependence and vulnerability. Finally, care for a chronically ill person often prompts pendulum-like swings, rebounding from a sense of absolute control to no control. Taken as a whole, the patient's significant other(s) can experience an often terrifying sense of lack of control, now relinquished to the laboratory which carries the power to confirm or deny recurrence, to the physician who has the sole ability to interpret and act on these results, and to the nursing staff, who can better care for the patient than the significant other.

Waiting:

Barckley (1967) vividly described a life-on-hold phenomemon for family members. "Families seem always to be waiting. They sweat out the biopsy and X-Ray reports, look at the clock a 100 time an hour while the patient is in surgery, wait for his sleep to come, for the doctor to call, or for a surcease from pain" (p.280). In 1984, Wright and Dyck interviewed 45 next-of-kin of hospitalized cancer patients. They cited waiting as one of their four primary concerns. "There was considerable frustration with the inevitable delays experienced with the bureaucracy of the health care system. Relatives expressed anger at waiting for admission, waiting for surgery and waiting for treatments to commence" (p.373).

Welch (1981) wrote an article entitled "Waiting, Worry and the Cancer Experience", suggesting that the "waiting/worry syndrome" is prevalent for family members during the diagnosis and treatment periods. "Fear of the unknown experienced by families occur each day as the patient is removed from view to receive therapy ...the family is left to fantasize about what goes on...thus separation or mutilation anxiety may become part of the waiting/worry syndrome" (p.16). Waiting exacerbates a new and fear-producing sense of dependence for all concerned. In anticipation of real or imagined potential distress, anxiety and tension are heightened. Consequently, a belief in personal control is often diminished, being replaced by painful feelings of grief, anger and helplessness.

Access to Information:

Information provided to patients by health professionals relative to their condition has been shown to enhance their sense of control, affecting a more rapid recovery when compared to patients who are not afforded access to information (Cromwell, Butterfield, Brayfield and Curry, 1977; Egbert et al., 1964). Similarly, it is generally accepted that information can have a positive impact on the coping behaviors of the next-of-kin. "Ultimately, despite their fears or denial of reality, families want information and support above all else from medical staff. Communication of factual information with candor and confidence gives the family more than hard data; it also fosters hope, that critical attitude necessary to family adjustment and survival" (Cassileth and Hamilton, 1979, p.243).

The Wright and Dyck study (1984) found that 49 percent of the patient's family members interviewed (n=45) reported that obtaining adequate information was a problem. As previously noted, Bond (1982) studied the communication patterns between 108 family members of cancer patients and the physician and nursing staff in a British hospital. She found poor and inconsistent interactions between family members and the patient's medical staff. Northouse's (1984) comprehensive literature review revealed that communicating with staff and feeling excluded from the focus of care are two of the dominant problems encountered by family members in the initial period of cancer treatment.

Tringali (1986) developed a 53 item Likert-type scale questionnaire to ascertain the cognitive, emotional and physical needs of family members of cancer patients. A convenience sample of 25 subjects was drawn from families accompanying patients to the medical or radiation therapy outpatient clinics of a cancer center. Subjects were stratified according the patient's phase of illness. This was defined as: 1) undergoing initial treatment 2) undergoing treatment for recurrent tumor growth or 3) follow-up treatment phase. Of the ten families in the initial treatment phase, five informational need statements received maximum scores. These were: 1) to have questions answered honestly 2) to know what treatment the patient is receiving 3) to have explanations given in terms that are understandable 4) to know what symptoms the treatment or disease can cause 5) to know when to expect symptoms to occur. The author notes that provision of basic information "prepares family members for supportive tasks such as reinforcement of treatment goals, reality-based encouragement, treatment of side effects and clarification of information delivered but perhaps not retained by the patient due to anxiety" (p.69). Although the small sample size limits generalizability of this study's results, it does reaffirm the importance of the informational needs of family members.

Omnipotent or Helpless:

There is a reality that no matter how well informed and competent the patient's significant other may be, no matter how in control they might come to feel in managing day-to-day issues, they essentially still remain unable to impact on the existence of a chronic disease in the body of one they love. "Personal efforts do not alter the biologic course of the malignancy. Feelings of helplessness evoked by inability to control effectively the destiny of the patient and the family are particularly difficult given one of the fundamental tenets of our society, that hard work and perseverance will bring success" (Cassileth and Hamilton, 1979, p.238).

Koocher (1979) has observed that caregivers often alternatively feel a sense of omnipotence, described as ultimate and total responsibility for the patient, ironically offset by a sense of total helplessness in the face of an unyielding illness. Often as the primary caregiver, the patient's significant other can feel as if on an emotional roller coaster, with the peak of omnipotence frequently being coupled with an overriding sense of guilt for their wellness, and despair at the present and potential losses incurred.

Means to reestablish a sense of control can be offered to the significant others of a newly diagnosed patient by making more readily available information about the disease and its treatment and by minimizing to whatever degree possible the waiting periods involved in the delivery of medical care. The reality of a lack of control over the disease process of a loved one can not be denied. Empathy and support for the fear, frustration and guilt engendered in the control/ no control situation of the patient's significant others may serve to effectively decrease the intensity of the mental gymnastics employed by the family members as a means to cope with a cancer diagnosis.

Sense of Purpose and Meaning

Giacquinta (1977) proposed a comprehensive model for analysis of family functioning when confronting cancer to assist nurses in developing intervention strategies. She singled out "search for meaning" as a discrete stage in the coping process in which "there is a need not only to find meaning for the present occurrence of cancer in the family, but also a need to ensure that this could not happen to another member" (p.1587). This stage is founded on an underlying sense of vulnerability in the face of one's own mortality.

An overriding fear of the future is often witnessed in the patient's significant others during a time of temporary normlessness and questioning of life's meaning. Cassileth and Hamilton (1979) believe one of the primary impacts of a cancer diagnosis is its tendency to upset family objectives and future plans. Living with uncertainty is identified by Northouse (1984) as a major challenge for family members. This finding is reaffirmed by the Wright and Dyck (1984) study in which "fear of the future" is cited as one of the four major concerns of the family members of adult cancer patients.

One method of coping is to avoid any thoughts of the future, for "to plan for the future almost invites the threat of loss" (Cohen and Wellisch, 1978, p.563). Parkes (1975) observed that one way family members accomplish this avoidance is to both focus on the patient and deny that they have any needs of their own. Confrontation with these fears and needs is necessary to restore psychological well-being in the next-of-kin. Giacquinta (1977) notes that nurses must strive to foster a sense of security which allows each family member to make a commitment to experience his or her changing identity.

Hope appears central to the energy required to redefine life's meaning and goals. Dufault and Martocchio (1985) studied 35 elderly cancer patients by means of participant observation over a two year period with the sole purpose to describe hope. A follow-up longitudinal study was also conducted with 47 terminally ill persons with varied diagnoses over a two year period to confirm their initial findings. Through this process, they came to define hope as "a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future goal which, to the hoping person, is realistically possible and personally significant" (p.380). The complexity of the emotion of hope is evident in their model which suggests that it is composed of two spheres (generalized and particularized) having six common dimensions; affective, cognitive, behavioral, affiliative, temporal and contextual. The intent of the model is to provide nurses with a method to help patients and family members find hope within the context of serious illness, believing that this is central to effectively coping with the situation.

Thorne (1985) conducted extensive interviews with eight families dealing with the cancer diagnosis and found hope essential to actively seeking reestablishment of normality and dignity and ultimate acceptance of the disease. Provision of hope was noted by Halman and Suttinger (1978) to be a critical element of family-centered care for people coping with cancer. In a descriptive study of critically ill patients conducted by Molter (1979), family members universally reported the importance of sustaining hope. The results of Tringali's (1986) study of 25 next-of-kin of cancer patients concurred with this finding. This limited research indicates that hope should be recognized as an important element in the adaptation process of the significant others of cancer patients.

The disequilibrium prompted by a cancer diagnosis often forces the patient's significant other to question life's meaning and purpose in the world. Restoration of psychological well-being is facilitated by allowing for and assisting friends and family members to sort out their troubled thoughts and feelings in their efforts to seek new meaning and purpose in their lives.

Communication and Expression of Intimacy:

The literature reveals that expression of intimacy between partners is one dimension of their relationship which can be greatly altered by both the physical and psychological realities of chronic illness. Open communication is central to intimacy and can be hindered by the way in which each individual comes to cope with the cancer diagnosis.

Jamison, Wellisch and Pasnau (1978) studied the psychological responses of 41 women who had undergone mastectomy surgery by means of an extensive questionnaire and several standardized tests. Although 42% of the subjects noted that the worst emotional period in the process was immediately following discovery of the lump, 89 percent of the women reported having little or no discussion about the emotional aspects of the mastectomy with their spouses prior to surgery. Similarly, 87 percent also reported little or no discussion about their concerns while in the hospital, improving to only 50 percent of the subject base reporting poor communication upon returning home.

Wortman and Dunkel-Schetter (1979) conducted an extensive literature review of the impact of cancer on interpersonal relationships and noted that open communication often becomes strained due to confused and ambivalent feelings of friends and family members. Poor communication can affect a relationship on multiple levels.

The communication of affection between cancer patients and their spouses was studied by Leiber et al. (1976). Subjects were comprised of 38 patients receiving chemotherapy for advanced cancer and 37 of their spouses. They were interviewed to discern their sociodemographic and medical history and took both a standardized depression inventory and the "Affectional Needs and Behavior Scale". Results showed that both patients and their spouses felt an increased desire for physical closeness and a decreased desire for intercourse. They found that affectional behavior was controlled to a greater degree by the patient than the spouse and therefore, not surprisingly, what was desired and what was obtained was correlated more closely for patients than their partners. "For patients of both sexes, changes in desire for sexual intercourse and for other physical contact were positively and significantly associated with changes in the frequencies of these behaviors. This was not the case for either of the spouse groups" (p.387). Gender differences were revealed with the following two high risk groups for emotional difficulties being identified: 1. husbands of cancer patients whose affectional needs are poorly met and infrequently expressed and 2. male patients and their wives who exhibited increased tension due to disparate needs and altered sex roles. This was a well designed and executed study in which patients were at an advanced stage of their disease. It would be helpful to study affectional needs at an earlier period in the disease process to see if findings remain consistent with those found in this research effort.

Dyk and Sutherland (1956) interviewed 57 patients who had had colostomy surgery and nine of their spouses to investigate their adaptation to the surgery. They also found serious sexual problems frequently reported by both patients and spouses.

In summary, it appears that the nature of physical intimacy becomes a point for renegotiation for many who must adjust to living with cancer. Research indicates that this can be particularly difficult for the spouse. The need to reestablish mutually satisfying affectional behavior should be acknowledged and addressed by the health care team in their support of the significant other who shares an intimate relationship with the cancer patient.

The significant others of a newly diagnosed patient can find their sense of control, their belief in the purpose and meaning of life and their level of intimacy with their loved one seriously threatened. Attention to these needs and concerns by health care providers allows a patient’s friends and family members to begin to redefine psychological well-being in the context of living with the chronic illness of their loved one.

Social Adaptation

There are two primary social ramifications of being a significant other of an individual with a cancer diagnosis. First, it appears that there is often a change in the nature and frequency of interactions with groups of peers and friends. Secondly, the financial impact of the disease can prompt a number of hardships for the next-of-kin. These two aspects of social adaptation will now be explored.

Social Life

"The extrafamilial effects of illness may lead to the family's withdrawal from active contact with the outside world so that friendships and affiliations are gradually discarded" (Anthony, 1970, p.57). Giacquinta (1977) discussed the first hurdle of informing others of the loved one's cancer diagnosis. She notes that the range of responses of others can often force a family into retreat, unable to bear the burden of supporting and informing others when they themselves feel unsupported and uninformed.

Cassileth and Hamilton (1979) noted that despite the fact that there is a powerful urgency permeating the family unit to maintain the status quo, the cancer diagnosis frequently "alters the constellation of external reference groups with which the family interacts" (p.241). A critical attribute of families who best coped with living with cancer were found to be those who created support networks (Thorne, 1985). In the intensive interviews conducted by Thorne, she reported that she was surprised at the number of anecdotes about other cancer families. It appeared to her that they comprised a "significant symbolic community...perhaps significant in preventing any sense of social isolation" (p.288).

Research regarding the changes in the social life of the cancer patient's significant others and its impact on their adaptation to the illness situation is sparse but common sense and the existing literature lends credence to the need and importance of these individuals remaining "socially viable". It appears that this often necessitates a restructuring of social affiliations.

Financial Concerns

Financial concerns are alluded to in a number of articles and studies. "Although for most families the bulk of medical costs related to cancer treatment is covered by third-party payers, personal expenses can be substantial and disruptive to the family's style of life" (Cassileth and Hamilton, 1979, p.239). In Welch's 1981 study with 41 family members of adult cancer patients, she found that 25 percent of the sample had to deal with changes in their work status in order to attend to the needs of their partner.

The self-esteem lost by individuals who are unable to maintain their premorbid work status can be significant (Dyk and Sutherland, 1956). This can create resentment, tension and strain as the patient's significant others assume a greater and greater percentage of the daily living tasks (Corbin and Strauss, 1984; Bruhn, 1977). "Changes in financial status can compromise the family's standard of living, further restrict normal social contacts and add to the problems and emotional strains experienced throughout the family" (Cassileth and Hamilton, 1979, p.239). The financial threat therefore has both serious logistical and emotional ramifications.

The significant others of patients will often face difficulty in the maintenance of social well-being in terms of both preserving a supportive and satisfying social network as well as their previous standard of living. Support and assistance should be offered to help these individuals deal with these difficult adjustment problems.

Physical Adaptation

The spouse of a chronically ill patient frequently reports psychosomatic symptoms (i.e. headaches, sleeping problems, et cetera), particularly during the diagnosis and immediate post-diagnosis phases. In Klein, Dean and Bogdonoff's 1967 study assessing the impact of illness upon the spouse, 76 percent of the 73 spouses interviewed reported an increase in their symptomatic levels. Twenty-five percent of Welch's (1981) sample noted psychosomatic symptoms.

In Cooper's (1984) interview study of the spouses of 15 lung cancer patients, twice as many spouses as patients reported the presence of signs of stress. The Dyk and Sutherland (1956) interviews likewise revealed that spouses were seemingly experiencing greater stress than the patients themselves. Googe and Varricchio (1981) interviewed patients and family members in their homes. They concluded that "family members who serve as primary caregivers are often in a state of unsatisfactory health" (p.27).

It appears that the partner of the chronically ill patient might in fact develop physical problems of their own in part due to the many strains imposed by the process of coping. Health care professionals may have the ability to intervene early to minimize these symptoms.

Summary

In summary, adaptation of the significant others of an individual newly diagnosed with cancer occurs in the psychological, social and physical realms. They often feel that their control is threatened. Information appears to be one vehicle by which to address this concern, empowering individuals to become effective team members. A second common response to illness is to question one's basic life philosophy. Hope appears essential to weather this often painful process of redefinition. A third major hurdle for the patient's significant others manifests itself in difficulties of communication and for some, reestablishment of a satisfactory level of physical intimacy.

The social welfare of the significant others of a cancer patient can be impacted by the diagnosis. Fear can arise from a sometimes profound sense of isolation. Social circles assume new forms. Financial demands can become a great burden and can prompt major changes in the social structure and plans of the family.

It is obvious that the newly diagnosed patient begins an on-going battle with the physical manifestations of illness. The physiological impact of the diagnosis on the patient's significant others is far less obvious yet has been cited by several researchers as an outcome of dealing with their loved one's disease.

"New directions and services need to be chartered for the family experiencing cancer...(however) it is beyond the scope of accumulated empirical evidence to offer firm prescriptive advice" (Lewis, 1983, p.197). Sound empirical studies are needed to form a more solid foundation upon which to build a health care system which adequately attends to the psychological and social, as well as medical aspects of health and illness.

Section Two:

Reactions to Radiation Therapy

It is estimated that one-half of cancer patients will receive radiation therapy during the course of their illness (Strohl, 1988). It is therefore surprising that the available pool of literature researching the reactions, concerns and needs of patients undergoing radiation therapy is fairly limited. Yet more scarce are articles relating the needs of the significant others of these patients. The one article which focused on family members of patients undergoing radiation therapy will first be reviewed. The literature review will then explore research relating to patient responses to treatment.

As previously mentioned, Tringali (1986) drew an unknown percentage of her non-random sample of 25 subjects from family members of individuals receiving outpatient radiation therapy in order to assess the needs of family members of cancer patients. The balance of the study subjects were drawn from individuals accompanying the patient to the outpatient medical oncology unit. A 53 item Likert-type scale questionnaire was administered to this group. Study subjects ranked cognitive needs as most important to them, regardless of the phase of the patient's illness. Family members sited the importance of the use of understandable terms and provision of honest answers as key to meeting this need. Also noted was the "need for hope and to trust the care provider's expertise and concern for the patient as a person" (p.67).

Since the analysis did not separately analyze the data of the subjects drawn from the radiation therapy department, it is not possible to say with certainty that these results represent the needs of this population. This study does, however, provide some insight into the heretofore unidentified concerns of the radiation therapy patient's significant others. It represents the only research focused on this population to date.

Several studies do exist which have studied the emotional and physical responses of patients receiving radiation therapy treatment. The Cassileth (1985) research (previously reviewed) indicates that the psychological status of the next-of-kin closely parallels that of the patient. For this reason the limited literature on the emotional response of patients to therapy will be presented, suggesting that a high degree of anxiety and numerous concerns present on the part of the patient are most likely evident in their significant others as well.

In 1977, Peck and Boland conducted a study in which 50 patients who were recently referred for radiation therapy were interviewed by a psychiatrist. The first interview occurred following their initial visit but prior to the first treatment. The second interview was conducted within one week of completion of treatment. The goals of the study were threefold: 1.) learn what patients are told when radiotherapy is prescribed 2.) explore attitudes toward their treatment and their illness 3.) assess how these attitudes are affected by the experience of receiving treatment. In the pre-treatment interview, 62 percent of the subjects were reported to show a "depressed mood with loss of their usual feelings of well-being and a definite state of sadness" (p.181). This was indicated by loss of sleep, and decreases in appetite, activity and sexual desire. Sixty-six patients were assessed as having a "significant degree of anxiety, as indicated by preoccupation with the spread of their disease, side effects of radiation therapy, doubts of relief of symptoms and survival" (p.181). It is important to note that the authors report a number of the subjects having had a previous psychiatric history, making interpretation of the data difficult to generalize.

The interviews revealed that patients had received "little or no information about radiation therapy reactions before treatment began. Most were informed by relatives and friends. Their accounts were usually inaccurate, pessimistic and alarming" (p.181). The psychiatrist observed that patients appear to be stunned on their first visit with the radiotherapist, showing a reluctance to ask questions and frequently forgetting information delivered to them at this time. During the post-treatment interviews, patients demonstrated heightened depression and anxiety. This finding is in keeping with that of Holland, Rowland, Lebovits and Rusalem (1979).

Holland et al. (1979) utilized the Gottschalk-Gleser Content Analysis method to assess emotional distress in 20 women undergoing adjuvant radiation therapy for breast cancer. Their goal was to determine the nature and level of emotional distress experienced by this cohort of women. Holland et al. found that patients were most fearful and anxious when they began radiotherapy. They noted that, "adequate explanation, information and reassurance given at this critical juncture by the radiotherapy technicians and the radiotherapist contributed to lessening anxiety" (p.353). Fear and anxiety lessened over the course of treatment, however, depression and anger increased over this same time period. This depression and anger was attributed to the fear engendered when considering a future without the reassurance of continuing medical treatment and to breaking ties with the clinic staff.

A similar study was conducted by Forester, Kornfeld and Fleiss in 1978. They enrolled 200 cancer patients to assess the nature and severity of their emotional distress. A modified version of the Schedule for Affective Disorders was administered to subjects at the beginning, midpoint and conclusion of radiotherapy as well as two weeks following the last treatment. They report that the sample manifested "a marked degree of restlessness, anxiety, apprehension, depression, social isolation and withdrawal" (p.962).

"Quasi-directed interviews" were conducted with 50 cancer patients undergoing radiation therapy in the Mitchell and Glicksman (1977) study. Sixteen percent of the subjects reported that the referring physician provided them with satisfactory information regarding their upcoming course of treatment, 32 percent report receiving only "partial information" and 52 percent stated that their referring physician was of no help in preparing for the experience. Sixty-three percent of the 19 individuals expressing initial fright during therapy were from this latter group. A depressed mood was reported by 82 percent of the study group, family difficulties by 46 percent and 85 percent expressed a wish to be able to "discuss their situation more fully". Interestingly, when queried as to who they felt they could discuss emotional concerns with, 82 percent said that the referring physician and radiotherapist were "not the people to bring emotional problems to", noting that they were too busy and should focus on the strictly medical aspects of treatment. The option of discussing their concerns with the clinic nurses was not brought up by any of the study participants which prompted the investigators to increase their efforts at educating patients about the availability of the nursing staff.

Kubricht (1984) set out to assess the therapeutic self-care demands expressed by outpatients receiving external radiation therapy. She enrolled 30 patients to participate in an open-ended interview regarding their self-care demands. They were asked to describe changes (if any) which occurred in their life since the radiation therapy began. "In descending order, the most frequent specific concerns were: tiredness or fatigue, awareness of mortality, belief in a supreme being, the need to rest, depression, loss of appetite, loss of weight, coughing, being careful not to wash off the red lines, skin redness and dryness, diarrhea, inability to do things he/she used to do, pushing oneself to be with friends and shortness of breath" (p.49). Each study subject expressed from 11 to 41 self-care demands. Many of these demands could be ameliorated with appropriate self-care techniques (i.e. nutritional counseling, energy conservation techniques et cetera).

King, Nail, Kreamer, Strohl and Johnson (1985) tracked the incidence of treatment side-effects in a non-random sample of 96 patients going through radiation therapy. The sample was stratified by treatment site to offer detail regarding the occurrence of specific side effects relative to the location of the cancer being treated. The study suggests that fears and anxieties could be lessened by offering the patient "anticipatory guidance" about what to expect and how to respond to side-effect symptoms.

Strohl, (1988) wrote a lengthy article about "The Nursing Role in Radiation Oncology: Symptom Management of Acute and Chronic Reactions". She stressed that, "radiation therapy is a difficult modality to comprehend. Being alone in a room and exposed to an invisible and powerful force that can destroy cells is an abstract experience that takes time and repeated information to become clear" (p.430). She observed that, "patients relate that this experience exemplifies the loneliness and isolation of the entire cancer experience" (p.430). Strohl asserts that nurses can play a critical role in offering information and support for radiation therapy patients and details the process of doing so.

Summary

These studies document high levels of patient anxiety and emotional distress, particularly during the initial phases of treatment, due to the physical and emotional adaptation to the disease. This appears to be partially attributable to lack of information regarding the treatment. Initial anxiety-oriented concerns are replaced by depression as the treatment nears its end, marking entry to a phase in which patients begin to deal with the realities of cancer as a chronic illness.

There is no reason to believe that the significant others of the patient have any greater knowledge of radiation therapy than the patient. In fact, the difficulty they generally experience in obtaining information may indicate that they have the same or less understanding of the extensive course of treatment that their loved one is about to undergo. This lack of knowledge will predictably heighten their anxiety, fears and emotional distress, paralleling the response of the patient.

The patient's significant other is typically included in the initial visit with the radiotherapist and many of the interactions with the nursing staff. However, they spend the bulk of their time in the waiting room, largely unaware of the sequence of events which patients experience in the course of their treatment. Educational efforts to lessen the element of the "unknown" felt by the patient's significant other(s) may serve to better facilitate their coping with the cancer diagnosis. Cassileth et al. (1985) would predict that this, in turn, will positively impact on the coping of the patient.

Section Three:

Use of Audiovisuals in Health Education

"There has been a tremendous expansion of materials that can be used individually or in combination to enrich educational programming. Print, film, filmstrips, tapes, radio and television, including interactive television, are all being utilized by schools, hospitals, and community agencies in designing new approaches to education-for-health" (Hamberg, 1985, p.7). The focus of this section will be directed to formal evaluation studies on the impact of videotapes as an educational tool used in the hospital setting for patients and their significant others. Testing of the effectiveness of slide-tape shows, filmstrips and audio programs will also be briefly reviewed.

Are videotapes an effective means of providing patient education? A limited number of empirical studies exist in the published literature which have sought to study this question.

Several studies have explored the usefulness of subjects viewing another person behaving calmly in the presence of a feared stimulus by means of a videotape (Melamed and Siegel, 1975; Padilla et al., 1981; Shipley, Butt, and Horowitz, 1978; Shipley, Butt, Horowitz, and Farby, 1978; Vernon, 1973). This modeling experience was thought to have the potential to reduce the anxiety and stress inherent in the feared stimulus situation.

Vernon (1973) selected 38 children who were under the care of one of two pediatric specialists and who were to undergo general anesthesia during their hospitalization. They were randomly assigned to either the experimental group, which viewed a 12 minute film within an hour prior to being administered preoperative medicine, or to the control group which did not see this film. A Global Mood Scale (completed by the professional staff), a projective test and a post-hospitalization questionnaire completed by parents six days and 30 days post-discharge were employed as measurements of the effect of the intervention. The professional staff reported that the children in the experimental group appeared significantly less frightened and upset during the time of pre-anesthesia administration than did the control group. No differences were apparent between the study groups at the time of the first post-hospital follow-up. The questionnaire administered 30 days post-discharge revealed that the experimental group was noted by their parents as being significantly less upset than the control groups.

Of greatest interest in this study was the immediate reduction in fear which was noted in the experimental group. It was unclear if the individuals completing the Global Mood Scale were blind to the study group which might potentially have biased their report. One-month follow-up data revealing significant differences between the experimental and control groups may be attributed to the film intervention, however, this seems unlikely given the limited scope of the intervention. If this result could be replicated, it would lend credence to the conclusions.

In 1975, Melamed and Siegel attempted to reduce the anxiety of children facing hospitalization and surgery by a film which was designed to prepare them for their hospital stay. Sixty children between the ages of four and 12 who had no prior hospitalization experience entered the study. Numerous instruments were utilized to assess levels of anxiety and fear. A "Behavior Problems Checklist" and "Parent Questionnaire" were also used as indicators of adjustment pre- and postoperatively. The authors reported that "the experimental subjects who had viewed the hospital peer-modeling film showed lower sweat gland activity, fewer self-reported medical concerns, and fewer anxiety-related behaviors than the control subjects at both the preoperative and postoperative assessments" (p.518).

Several other modeling studies have also been conducted with adult patient populations. Shipley et al. (1978) conducted two studies in which they attempted to reduce patient stress relative to the high stress medical procedure of endoscopy. In the first study, 60 patients undergoing their first endoscopy were enrolled as subjects. In the follow-up study, 36 patients having previously undergone the procedure were employed. In both research efforts, one of the experimental groups viewed a videotape of an individual undergoing the procedure one time prior to undergoing their endoscopy. The second group viewed the videotape three times. A control group simply underwent the procedure with standard preparation from the staff.

In the first study where the subjects were having their first endoscopy procedure, the control group exhibited the greatest degree of anxiety, the experimental group viewing the videotape one time revealed a moderate degree of anxiety and those viewing the videotape three times had the lowest anxiety as measured by heart rate and independent ratings from the medical staff. Patients were then stratified into two coping style groups, repressors and sensitizers. Sensitizers typically seek information about a stressor as a means of preparing for the experience. Repressors are generally overtly non-anxious and deal with the impending stressful situation by not thinking about it. When analyzed according to coping style, some interesting differences were found in this first study. Sensitizers exhibited a monotonic decrease in anxiety as a function of number of viewings of the videotape. One viewing of the videotape peaked the anxiety level of the repressors. Anxiety did decrease for this group following three viewings.

The second study employed individuals who had previously gone through endoscopy. Contrary to the findings in the first study, there was no significant difference in extinction of levels of anxiety noted between groups. The analysis was then stratified by coping style. An identical pattern of anxiety reduction as in the first study was noted in the sensitizer group. The heart rate of the repressor group increased as a function of the number of viewings of the videotape. The findings of these two studies lead Shipley et al. to suggest that "sensitizers be prepared extensively and repressors left alone or at least left with their defenses" (p.490).

Padilla et al. (1981) studied the effect of four different filmstrips on distress levels of 50 patients undergoing nasogastric intubation. The content of the four filmstrips were as follows: 1.) depicting the procedure only 2.)depicting the procedure with common distressful sensations 3.)depicting the procedure with common coping behaviors 4.) depicting the procedure with coping behaviors to relieve common distressful sensations. Subjects were stratified according to their preference for control or no control over the course of the procedure. The results revealed that the filmstrip showing the procedure and providing sensory and coping behavior was effective in decreasing the distress for both groups. The sensory information provided by the filmstrip also increased the subjects reported willingness to repeat the procedure and decreased their discomfort.

These modeling studies have attempted a preliminary analysis of the influence of various types of information and control on the emotional response of patients to stress. They make clear a very complex interrelationship between the predisposing psychological factors of the patient and the nature of the intervention strategy delivered. Further studies are needed to better understand when patient intervention (or intervention with their significant other) will serve to either increase or decrease their coping behavior. This would be helpful information to those involved in patient education, however, realities of the present system make it difficult to realistically discern and tailor educational interventions to the specific psychological status of the individuals in the health care system.

A number of additional studies have attempted to look at the effect of audiovisual programs for adult patients without stratifying for subject preferences for information or control. They suggest that although the interventions may not equally help all who view the audiovisual materials, subjects are not hurt by the experience.

Lawson et al. (1976) developed and tested the efficacy of a videotape tutorial program designed to improve dietary adherence for patients with chronic renal failure. Four 10-minute videotapes were produced. One tape was shown to the patients during each dialysis session. The total length of the tutorial program therefore was four days. The tapes included a self-test at their conclusion. Sixteen patients were randomly chosen from the 30 renal patients who were receiving care in the unit. The sample was stratified by educational level, Group A being 8 subjects having less than a tenth grade education and Group B being those with a tenth grade education or better. This issue was important to the investigators as 50 percent of their patients had very poor or no reading skills.

Pre- and post-information tests were given to all 16 subjects. Additionally, a diet history was taken on the day of the pretest and day of the post-test. Limitations of validity and reliability of self-report diet histories were recognized by the authors but it was suggested that consistency of the error on both the pre- and post-tests lent credibility to its analysis.

The results revealed that although Group B (those having a higher educational level) had a higher mean score at the time of the pretest, both groups gained a significant amount of knowledge, resulting in approximately equal scores following the intervention in both groups. Some positive changes in reported diet history were evident, although they did not reach a level of significance. It does appear that information was imparted which for some, prompted modification of existing dietary behaviors. Research regarding the durability of both informational and behavioral changes would be helpful. Additionally, an increased sample size would give strength to the findings.

An impressive aspect of the Lawson et al. study is its attention to development of materials for patients having lower educational and literacy levels. This is an extremely important population to target as often their socioeconomic status impacts on their ability to adequately attend to their self-care needs.

For a 10 month period at St. Francis Hospital in Connecticut, all patients admitted to the facility for a myocardial infarction (M.I.) or other cardiac conditions were invited by Bracken, Bracken and Landry

(1977) to enter one of two educational interventions. The hospital had produced four videotapes which covered essential areas of concern regarding the post-heart attack rehabilitation process. They were aired on four consecutive days over the in-house television network. The nurse who was featured in the video also personally intervened to answer questions after each program. The second intervention consisted of a lecture program held on four consecutive days. A nurse met with attendees individually after the program to answer any questions.

Patients were briefly interviewed prior to the intervention and went through a more extensive post-intervention interview, completing a battery of tests.

The total number of subjects initially entered into the study was 331, however, of the 166 assigned to the lecture group, only 61 completed the intervention. This is a dropout rate of 63 percent. In the video group, 165 entered the study, 90 completed the program and 75 (45 percent) did not finish. Both dropout rates were dramatic and create concerns about the validity of the data.

It did not appear that any data other than demographics were obtained on the pretest. The study focused only on a comparison of both knowledge and psychological variables of the two groups at the time of completion of their respective interventions. Analysis showed no significant difference between the two groups relative to knowledge. Some difference in psychological data was unearthed when the analysis was stratified according to age, however, the relevance of this information was never clearly stated in the study.

Two basic methodological concerns about this study warrant attention. First, there was no assessment of pre-intervention knowledge via either a pretest or use of a control group, making it impossible to assess if learning occurred. Secondly, both interventions relied heavily on a lecture format which is of questionable value as an educational technique for those in a high stress, physically depleted immediate post-diagnosis phase. This might have contributed to the high dropout rate. The summary suggests that videotapes are a viable means of providing patient education with greater compliance noted than with the use of the lecture format. However, the design problems of this study make it difficult to draw any clear conclusions.

A video-based educational intervention for patients with chronic obstructive pulmonary disease was developed by Black and Mitchell (1977) with the stated purpose being to increase factual knowledge about the illness. In addition to the videotape, an audiotape talked the patient through the dismantling of a lung model. The study was designed to assess knowledge gain.

Black and Mitchell reported a sample size of 65, however, in reality the assessment instrument used and the timing of delivery of the instrument was modified twice during the course of the study. Pretests and post-tests were therefore obtained on 55 subjects. Although the instrument was changed midstream, a significant improvement in the knowledge of subjects was found.

Once again, the poor design of this study makes difficult any meaningful interpretation of its data. It would, however, be relatively safe to infer that some knowledge was imparted by the intervention.

A study was developed by Moldofsky et al. (1979) to examine the level of knowledge of 40 patients exposed to an asthma education videotape. Thirty-nine controls were obtained and served as a basis of comparison on a knowledge test which was administered to the experimental group following the intervention. A follow-up test was administered 16 months after review of the video. The medical status of the groups were also analyzed at this time.

Results revealed a significant knowledge gain by experimental subjects immediately following the viewing as compared to the controls. No appreciable knowledge difference or difference in medical status was found during the 16 month follow-up. The average length of time subjects had lived with asthma was reported to be 17 years. It may be that the presentation entitled, "Living with Your Asthma" was not relevant to the on-going concerns of these viewers, effecting short term but not long term retention. A cohort of newly diagnosed patients might have been a more appropriate subject base. Additionally, a decrease in the follow-up time interval and more specific medical status markers would have greatly enhanced the study design.

In 1982, the University of Pennsylvania Cancer Center developed four cancer education videotapes and assessed their effectiveness in terms of knowledge, anxiety and impact on the viewers' ability to communicate with staff. Cassileth et al. enlisted the cooperation of 240 patients, family members and friends, having these individuals complete an immediate pre- and post-knowledge test and a standardized anxiety test. They were also asked to fill out an evaluation questionnaire following the viewing.

Knowledge tests were comprised of five to six questions for each videotape. Results showed a significant increase in knowledge for all four videos. The subjects' anxiety levels decreased significantly at the time of post-testing. The evaluation showed an overall favorable response to the content and format of the films. An open-ended question was included to discern if subjects felt the programs "would or would not affect communication with staff". The "majority opinion" (63 statements) was that communication would be facilitated. The authors found that the videos were particularly useful for less well educated and minority populations. It is also noteworthy that relatives displayed significantly higher anxiety levels than did patients on both pre- and post-tests. This is consistent with data cited in Section 1 (Cooper, 1984; Dyk and Sutherland, 1956).

Williams and Manske (1987) decided to test the use of a videotape as the primary vehicle for teaching crutch walking to an non-random, unmatched sample of 55 first-time crutch walkers. It was felt that the audio-visual tape was "an accurate, consistent, and cost-effective teaching tool" which promised to "free emergency nurses from a repetitive, time-consuming task while providing for optimal patient teaching" (p.156).

The 30 control group subjects were given the usual nonstructured teaching generally provided by the emergency department staff members to first-time crutch walkers. The experimental group viewed a 13 minute videotape on this topic. All subjects were then tested via both a written knowledge test and a performance test. When total test scores (both written and performance) were analyzed, those individuals viewing the videotape had a significantly higher test score than the control group. A comparison between the experimental and control groups' performance on each individual test was then made. A significant difference remained between the groups on the performance test but was not evident with the knowledge test group comparison.

Williams and Manske cautioned that the data suggested that test score results (particularly on the scoring of the performance test) might have been unduely influenced by the varying committment of the testers. It was also not clear whether the testers were blind to the subject study group, an additional cause for bias. The staff members did note their enthusiasm about the tape, and in fact reported that the videotape subjects required less reteaching. The researchers conclude, "There is reason to believe that audiovisual teaching tapes could be effective in a number of patient teaching situations" (p.159).

The medical staff of a 300-bed hospital in the western part of Holland decided to prepare a video program on footcare to address a problem in adequately meeting this educational need for diabetic patients. Bakker (1987) enrolled 40 subjects in a study to test the impact of this teaching tool. They were asked to complete an eight question pre- and post-test immediately before and after viewing a 28 minute videotape. He reported that the percentage of patients correctly answering the pretest questions were 69% and rose to 91% at the time of post-testing. When these subjects were interviewed after a six month period following posttesting, Bakker reports that "a majority of them stressed that they had followed up at least some of the advice they had not taken heed of before" (p.334).

The study design would have been strengthened if a randomly selected control group were employed. Also, it was not clear how the study group was drawn. No delay in post-testing following viewing the videotape may well have tested only for short term retention of information. Finally, six month self-reported behavior changes were not definitive evidence of the impact of videotape viewing. Despite these limitations, this study does document the world-wide interest of health professionals to search out and test innovative methods of meeting the educational needs of patients.

This fact is further documented by a London-based study conducted by Mulrow, Bailey, Sonksen and Slavin in 1987. The purpose of their study was to determine the effect of employing an audiovisual program for patients with non-insulin-dependent diabetes and who had limited literacy. For this purpose, 120 individuals were assigned to one of three intervention groups: 1. Groups of three to five met monthly for a period of six months with a nurse clinician trained in diabetes education. A 30-minute videotape was viewed at each session. This was accompanied by written materials. 2. Groups of three to five met monthly for a period of six months with a nurse clinician trained in diabetes education. The first session was a structured educational session of one hour's duration. The remaining session were open-ended and lasted 30 minutes. 3. Subjects received the same one-hour lecture provided to subjects in group 2 but received no follow-up education. Subjects were given a baseline questionnaire regarding their medical history, sociodemographics and dietary questions at the time of randomization to a study group. Medical indicators were also noted (i.e. weight, nonfasting blood sample) at this time. Subjects were given a short test about diabetes and its management at month 7 and the medical indicators were once again recorded. These same measures were again taken in the eleventh month.

Results revealed no differences between experimental groups beyond a short-lived weight loss recorded at the seventh month testing interval. It is essential to note that 13 percent of the subjects dropped out of the study before the seven month follow-up point. By month 11, the drop-out rate had risen to 32 percent of the total subject base. Additionally, the authors report that compliance with monthly scheduled meetings was poor. Only approximately half of the patients in groups one and two attended more than half of the scheduled sessions. The drop-out rate coupled with the non-compliance of subjects to complete the intervention significantly weakens any meaningful interpretation of the study data.

Three studies have focused on the assessment of the impact of varied audiovisual educational interventions on radiation oncology patients (Israel and Mood, 1982; Johnson, Nail, Lauver, King and Keys, 1988; Rainey, 1985). Israel and Mood (1982) studied the effect of viewing three slide-tape presentations on knowledge gain in 36 cancer patients undergoing radiation therapy. One program was shown prior to treatment and discussed the procedures entailed in radiation therapy. The second program, shown one to three weeks into the treatment course, discussed side effects of therapy. The final program dealt with common emotional reactions to treatment and was viewed four to seven weeks into treatment. All subjects viewed all three programs. The control group completed a knowledge assessment prior to viewing the slide-tape presentation. The experimental group was given the knowledge assessment following viewing of the program. Results showed statistically significant differences in control and experimental groups for all three programs, demonstrating a knowledge gain attributed to viewing of the slide-tape show.

Rainey (1985) secured a sample of 60 patients receiving radiation therapy for the first time. The first 30 individuals entered into the study were treated in the usual manner but took knowledge, anxiety and general mood state tests during the first and last weeks of treatment. The experimental group took the same series of tests but saw a 12-minute slide-tape program prior to the first testing session. The program was reported to cover the following information : 1. introduction to the staff 2. review of the equipment 3. outline of the treatment procedures 4. explanation of what the patient will see, hear and feel during treatment 5. basic information about how radiation therapy works 6. dispelling of common misconceptions 7. encouragement of information seeking behavior. Additionally, all subjects took two tests which categorized them as either using "vigilant-avoidant" or "repression-sensitization" coping strategies.

Rainey (1985) found that patients in the experimental or "high-information group" showed significantly greater knowledge about radiation therapy at the time of the first testing. It is important to note that testing did occur immediately following viewing of the videotape and therefore may predominantly reflect only short term retention capabilities of subjects. This knowledge effect was not apparent in the second testing session.

The subjects in both groups could not be distinguished at the time of the first testing session according to degree of emotional distress. There was, however, a significant difference between groups when tested in the last week of treatment, with high-information subjects reporting less anxiety and a lower total mood disturbance. When the data were analyzed relative to coping style, no effect was noted. This lead the author to suggest that fear of imposing "untoward effects for avoiders and repressors" by subjecting them to an educational intervention is unfounded according to the results of this study.

Although the Johnson, Rice, Fuller and Endress (1978) study's educational intervention consisted of an audio but not visual approach to imparting information, it warrants review due to the fact that it deals with the issues so closely related to the researcher's study design. In this study, 81 patients who were to undergo cholecystectomy surgery were randomly assigned to one of three groups: 1. no experimental information 2. procedural information or 3. sensory information. The content of the procedural information audiotape addressed "things that the staff would do for and to the patient" (p.9). The sensory information audiotape included procedural information but emphasized "the sensations surgical patients experience" (p.9). The sample population was also split into either an instruction or no instruction study status, creating a 2x3 experimental factorial research design. The "instruction" subject population received instructions via an audiotape about deep breathing, coughing, leg exercises, turning in bed and getting out of bed. Patients also reviewed this information with the nursing staff following listening to the tape.

Findings revealed that descriptions of typical sensations to be experienced pre- and postoperatively significantly reduced the length of postoperative hospitalization and the time after hospital discharge before patients ventured from their homes. Procedural information alone did not improve the patient's rate of recovery as measured by these two markers. When study subjects were stratified according to whether they exhibited low or high fear before surgery, the mood state of highly fearful patients significantly benefited from all three interventions.

Because this study population was predominantly female, Johnson et. al. (1978) secured a sampling of 68 herniorrhaphy patients who were primarily males. A comperable study design was executed but resulted in "meager evidence that either type of intervention had an effect on herniorrhaphy patients' postoperative recovery" (p.15). It was felt that this might have been attributable to the differences in intensity of the postoperative recovery period for the two types of surgery or to sex differences.

In keeping with her interest in studying the content of information provided in health education efforts, Johnson et al. (1988) again conducted a study utilizing audiotapes to deliver concrete objective information to 84 men undergoing curative radiation therapy for prostate cancer. Critical attributes of this information were identified as, "1. descriptions of the physical sensations experienced by most individuals, that is, what can be expected to be seen, heard, felt, smelled and tasted, 2. the environment in which treatment will take place, and 3. the temporal characteristics of treatment" (p.47). She suggested that, "an unambiguous cognitive representation is believed to increase patient' confidence in their abilities to cope with the experience and to foster problem-solving approaches to coping" (p.47). It is interesting that although the importance of sensory information was stressed, an audio format was selected, negating the additional effect of linking auditory information with visual perceptions of the experience. Despite this fact, the researchers were successful in reducing the degree of disruption in usual, daily functioning in the experimental group (n=42), as measured by the "Sickness Impact Profile". The subjects' mood state was not affected by the treatment and generally reflected very little mood disturbance in the total study population.

Johnson et al. (1978 and 1988) provided valuable insight into important content issues for patient education resource development which heretofore had not been formally studied. "In the studies of the effects of information about the experience on patient's ability to cope with surgery, little attention has been given to the content of the information" (p.7). This is also true for studies conducted with other patient populations. Johnson (1978) further clarifies that, "In the main, the content of the information has consisted of descriptions given in nursing manuals and textbooks of nursing and medicine...but little emphasis has been placed on the experience from the patient's vantage point" (p.7). Her research findings infer that this approach to the delivery of information impedes the potential positive impact of audio educational interventions.

Findings with all three subject groups did highlight the complex interrelationship between the emotional and behavioral responses of patients, indicating the need for further research in this area.

The use of a filmstrip to teach diabetic self-care (Young et al., 1969), slide-tape presentations for asthmatic children and their mothers (Sly, 1975), for patients in a venereal disease clinic (Alkhateeb, Lukeroth and Riggs, 1975), for individuals using steroids (Olsen and DuBe, 1985) and bronchodialators (Darr, Self, Ryan, Venderbush, and Boswell, 1984) , for patients about to undergo surgery (Colton, Lowi and McCann, 1986), and those recovering from a myocardial infarction (Marland and Havik, 1987) have also been studied. Knowledge increases were attributed to the audiovisual interventions in all cases.

Summary

The paucity of research regarding the impact of educational videotapes used for patient education coupled with the many methodological problems inherent in these studies does not allow for great insight into the potential of this medium. All that appears definitive is that increases in knowledge will most likely be demonstrated immediately following videotape viewing. Reduction of anxiety has also been frequently reported. The potential of longer term retention or impact on behavior relative to learning objectives remains unknown.

A totally unexplored field to date is the impact of videotapes on the significant others of cancer patients. Cassileth et al. (1982) offered preliminary data indicating that these individuals demonstrated a knowledge gain and a decrease in anxiety due to videotape viewing. This was measured by an immediate pre- and post-test relative to viewing the videotape. For this reason, results are restricted to demonstration of short-term retention of information and short-term anxiety reduction only. Anxiety reduction may have been relative to the content of the videotape but it may also have been influenced by clarity about the task at hand. Further research to discern long-term retention of material and impact of videotape viewing on the emotional state of the patient's significant other is needed to better understand the potential use of this medium as a means of helping these individuals cope with the patient's illness.

CHAPTER 3

METHODOLOGY

The purpose of the study was to evaluate the impact of two educational interventions on the knowledge levels regarding radiation therapy and state of emotional dispositions of the significant others who accompany cancer patients to outpatient radiation therapy at the University of Massachusetts Medical Center. More specifically, the reported impact upon significant others of viewing an educational videotape in addition to the usual staff educational efforts was determined.

Study Design

Radiation Therapy Process

In order to understand the study design, it is necessary to first understand the sequence of events which the patient and his or her significant other undergo when entering into a course of radiation therapy. The process of receiving radiation therapy treatment consists of three phases. In the "Initial Visit" the patient and the patient's significant other complete the necessary registration information and meet with the radiation oncologist for an overview of the treatment process. The radiation oncologist then conducts a physical examination of the patient.

The second appointment in the clinic is termed a "Simulation Visit" at which time the exact method of treatment is defined by use of a simulation machine. This process takes approximately one hour to complete. During simulation, the patient's significant other remains in the waiting room.

A minimum of approximately two days following the simulation, the patient begins the course of daily radiation therapy, lasting varying lengths of time but averaging six weeks in duration. Immediately prior to the first treatment, one of the clinic nurses meets with the patient and his or her significant other in order to conduct a nursing assessment and obtain informed consent. The patient then proceeds through the course of radiation therapy, meeting privately with the physician once a week unless a request is made to include the patient's significant other.

Study Protocol Summary

All significant others of cancer patients coming to the University of Massachusetts Medical Center for radiation therapy from June, 1986 through October 1988, who were screened by the staff, met the inclusion criteria and who agreed to be part of the study were randomized to one of two treatment groups. The Usual Treatment group took part in the standard educational interventions employed in the radiation therapy clinic. The Videotape Treatment group viewed an educational videotape in addition to the standard educational interventions. Pre- and post-tests were administered to subjects to assess knowledge levels and states of emotional disposition. The Videotape group also completed Videotape Assessment questionnaires. Additionally, a convenience sampling of approximately one-half of the subjects in each intervention group were interviewed.

The following diagram notes critical points in the study design:

```
1     2               3         4          5
*I---I*-------------I-*-I-------*I---I---I-*-I---I

Initial           Simulation     1   2   3   4   5
 Visit              Visit         Treatment (weeks)
```

Key: Point 1: Subject eligibility assessed. Informed consent obtained. Knowledge Assessment and Mental Health Inventory pretesting for all subjects completed.

Point 2: Videotape Treatment subjects choosing to view the video in the home setting were given the tape (N=12).

Point 3: Videotape Treatment subjects who chose to view the video in the hospital setting were shown the video (N=2). Subjects who viewed the video at home returned the tape.

Point 4: All subjects were given the Knowledge Assessment post-test.

Point 5: All subjects were given the Mental Health Inventory post-test. Videotape Treatment subjects completed the Videotape Assessment tool. Approximately one-half of subjects in each group were interviewed.

Procedure

1. Pre-Initial Visit

Every effort was made to contact new referrals to the clinic by phone prior to their first visit to the unit (see Appendix A). The research staff called the patient and assessed whether there would be a "significant other" who would be accompanying them to treatment. If the patient responded that a significant other would be with them for the initial visit and that individual lived in the patient’s home, the research staff briefly described the research effort to the patient and then asked to talk to this person. If the individual was home and able to come to the phone, he/she was told that a study was being conducted in the clinic and asked if he/she would be willing to come to the clinic 30 minutes prior to the patient’s first visit so that the researcher could talk to that individual about the study. If the person was agreeable, an appointment was made. If the individual was not agreeable, the significant other was excluded from the study. The nursing staff estimated that approximately three out of every four individuals contacted were either excluded in keeping with the study inclusion criteria, or preferred not to be involved. It was their observation that refusal to be part of the study was greatly attributable to the significant other's existing stress level.

When the patient and the significant other who expressed an interest in learning about the study arrived at the clinic, the nursing staff member assigned to this individual met with the potential subject in a separate room to ascertain his or her willingness to enter the study (see diagram point 1). The patient was always invited to accompany the significant other to this meeting.

An intake form was first completed by the potential subject (see Appendix B). This form served as a vehicle to assess if the individual met the basic inclusion criteria. If this person did not meet the inclusion criteria, the meeting was terminated. If the inclusion criteria were met, the research assistant briefly described the purpose of the study and carefully reviewed the "Informed Consent" form (see Appendix C). If the individual agreed to be a study participant and signed the "Informed Consent" form, he or she was asked to complete the "Radiation Therapy Knowledge Assessment" (see Appendix D) and the "Mental Health Inventory" (see Appendix E). The nursing staff also assessed the severity of the patient's condition and noted the patient's date of birth (see Appendix F).

The subject was then randomly assigned to one of two treatment groups. The randomization sequence was developed by the researcher using a random table of numbers. If the subject was in the Videotape Treatment group, the individual was told that he or she would be involved in an educational intervention during the next visit to the clinic while the patient was being simulated or would be sent home with a videotape to be viewed prior to the simulation visit (see diagram Point 2). In the latter instance, the tape was returned to the clinic at the time of the patient's simulation. The nursing staff noted the site of viewing on the Supplemental Subject Intake Data form (see Appendix F). Subjects randomized to the Usual Treatment group received no special educational intervention.

2. Simulation Visit

During the time of the patient's simulation visit, one member of the nursing staff arranged to have the Videotape Treatment subjects who chose to see the video in the hospital, view the radiation therapy educational film (see diagram point 3). If the subject had chosen to take the videotape home for viewing after the initial visit, either the subject or his or her significant other returned the tape at the time of the simulation visit. No intervention was made with the subjects assigned to the Usual Treatment group beyond the staff's usual educational efforts, described in greater detail on page 79. It was not mandatory that either subjects who had viewed the videotape at home or Usual subjects accompany the patient to the simulation visit.

3. Pre-First Treatment Visit

Prior to any nursing or medical intervention(s) on the patient's first day of treatment, one member of the nursing staff administered the Radiation Therapy Knowledge Assessment post-test (see diagram point 4).

4. Third Week of Treatment

All subjects were contacted to schedule a meeting during one of the patient's treatment visits in the third week of therapy. If the subject was going to be interviewed during this session, a trained outside interviewer initiated the contact and arranged for the meeting. If this subject was not going to be interviewed, a member of the nursing staff called the subject to arrange for post-testing. During this session, the Mental Health Inventory post-test was administered to all subjects. The Videotape Assessment was completed by all individuals in the Videotape Treatment group (see Appendix G). A semi-structured interview regarding their clinic experience occurred with a convenience sampling of approximately one-half of the subjects in each intervention group (see Appendix H).

Treatments

As previously noted, subjects were randomized to one of two treatment groups:

1. Usual Treatment

The usual treatment of a significant other of a patient being seen at the University of Massachusetts Medical Center radiation therapy clinic consists of 1. joining the patient during his or her initial discussion with the radiation oncologist at the time of the initial visit and 2. being present when the nursing staff conducts a nursing assessment and obtains Informed Consent from the patient immediately prior to the first treatment. Other interactions with the medical and nursing staff occur on an as-needed basis. The nursing staff is readily available in person or by phone to answer the questions and concerns of patients and family members. It is not uncommon for the nursing staff to informally talk with the family members at the time of the patient's treatment. The physician staff is also accessible to family members upon request. If deemed helpful, family meetings will be held during the treatment program. Subjects in this group received no additional structured intervention immediately prior to or during the simulation visit.

2. Videotape Treatment

In addition to the usual treatment, the subjects in this group viewed the "Radiation Therapy: A Patient Perspective" videotape either in the hospital during the patient's simulation visit (n=2) or took the tape home for viewing following the initial visit (n=13). The tape was returned to the clinic at the time of the patient's simulation.

<u>Videotape Description</u>

The author of this research was the producer of the intervention videotape. Program content was developed by working in concert with the nursing staff and radiation oncologist to define key informational and support needs of patients and family members. One format consideration which the present researcher felt to be central to effectively meeting the needs of viewers, was the use of patients as the primary conveyors of information. Only in the Johnson studies (Johnson, 1973; Johnson & Leventhal, 1974; Johnson, Kirchhoff, & Endress, 1975; Johnson, Morrissey, & Leventhal, 1973; Johnson & Rice, 1974; Johnson et al., 1978; Johnson et al., 1988) has this format consideration been acknowledged as essential to the effectiveness of an audio or visual health education presentation. "Informational interventions that describe experience from the experiencing person's vantage point have been found to consistently facilitate coping with threatening events in the laboratory (Johnson, 1973; Johnson & Rice, 1974) and in the health care settings (Johnson & Leventhal, 1974; Johnson, Morrissey & Leventhal, 1973; Johnson, Kirchhoff & Endress, 1975)" (Johnson et al.,1978, p.7). For this reason, a group discussion with patients, facilitated by the radiation therapy nurse, was the basis for the study's videotape. One of the group's members was also followed through the treatment process. The patient moderated this video segment. The radiation oncologist presented a brief overview of radiation therapy in the context of the patient's first visit.

It was believed that this technique would impact on the viewer in several important ways: 1. Viewers would understand that their questions were both legitimate and shared by others. 2. Viewers would gain reassurance by visually having witnessed, from a patient's perspective, what a treatment is all about 3. Viewers would gain hope by seeing individuals who had successfully completed radiation therapy 4. Viewers would recognize the clinic staff's respect for and understanding of the patient's issues and therefore would feel empowered to more readily approach the staff in seeking answers to their questions.

Subject Inclusion Criteria

The subject population was comprised of the significant others of cancer patients receiving radiation therapy at the University of Massachusetts Medical Center who planned to accompany the patient to the clinic for the initial visit, the simulation visit (for those chosing to see the videotape in the hospital setting), the first treatment visit, and for one of the treatments in the third week in the course of therapy. "Significant other" was defined as any individual who was emotionally involved in the well-being of the patient and who was not merely an acquaintance. This may have been a spouse, partner, child, relative or close friend. Subjects were required to be physically and mentally able to participate in the study, able to hear, read and understand English, aware of the patient's cancer diagnosis and 18 years of age or older. Individuals were excluded if they had previously consistently accompanied another patient to treatment or had undergone a course of radiation therapy themselves (see Appendix I).

The study was limited to the significant others of patients who were undergoing their first course of radiation therapy. These individuals were new to the system and therefore were assumed to have relatively high information and support needs.

The significant others of patients who were receiving radiation therapy treatment for a common skin cancer (basal or squamous cell) in its early stages were also excluded from the study due to the very high cure rate of the disease and minimal nature of the threat to the patient's overall health.

Subjects

A total of 29 subjects who met the criteria noted above were enrolled in the study. They were randomly assigned to either the Usual Treatment group (n=15) or to the Videotape Treatment group (n=14).

Comparison of the Usual and Videotape groups relative to subject age and education level, and patient age was done by means of t-tests for uncorrolated means. Nominal data, consisting of a rating of the severity of the patient's condition, sex, relationship to patient, diagnosis, and average time since diagnosis, were compared by means of chi square tests. No significant differences between the Usual and Videotape Treatment groups were found on any of these demographic factors, as noted in Table 1 (see page 86). A summary of subject demographic data is found in Table 2 (see page 88).

Subject ages were well distributed, ranging from 23 to 79 years old. A comparable spread in ages of the patient group was found (range of 36 to 83 years old).

Table 1

COMPARISON OF THE USUAL AND VIDEO TREATMENT GROUPS ON DEMOGRAPHIC VARIABLES

	Usual[a]		Video[b]				
	Mean	SD	Mean	SD	t	P	DF
Subjects' Age	58.7	14.4	55.7	15.5	.54	.59	26
Patients' Age	62.3	10.1	60.7	14.6	.34	.73	23
Educational level (last comp. grade)	12.1	2.6	13.4	1.9	-1.5	.14	26

	Usual Frequency	Video Frequency	Chi Square	P	DF
Severity of Cond. (ambulatory)					
- fully	14	12	3.12	.21	2
- moderately	1	0			
- marginally	0	2			
Sex					
- female	11	7	1.67	.19	1
- male	4	7			
Relationship to Patient					
- friend	1	0	8.98	.25	7
- spouse	10	10			
- daughter/son	0	2			
- other family mem.	0	2			
- father/mother	1	0			
- niece/nephew	1	0			
- brother/sister	1	0			
- aunt/uncle	1	0			
Diagnosis					
- ovarian/uterine	4	1	6.32	.39	6
- breast	2	4			
- lung	3	1			
- colon/rectum	0	1			
- leukemia	1	0			
- pancreatic	1	0			
- unspecified	4	5			

Continued next page

Table 1 continued:

	Usual Frequency	Video Frequency	Chi Square	P	DF
Time since Dx					
- < 1 week	0	2			
- 1-2 weeks	1	0			
- 3-4 weeks	2	2	5.88	.21	4
- 5-6 weeks	3	0			
- > 6 weeks	8	8			

[a] n=15
[b] n=14

Table 2

SUMMARY OF DEMOGRAPHIC VARIABLES OF STUDY SUBJECTS[a]

	Mean	SD	Range
Subjects' Age	57.3	14.7	23-79
Patients' Age	61.1	12.3	36-83
Educational level	12.7	2.3	7-17

	Frequency	Percent
Severity of Condition		
Fully Ambulatory	26	89.7%
Moderately Ambulatory	1	3.4%
Marginally Ambulatory	2	6.9%
Sex		
Female	18	62.1%
Male	11	37.9%
Relationship to Patient		
spouse	20	69.0%
daughter/son	2	6.9%
father/mother	1	3.4%
niece/nephew	1	3.4%
brother/sister	1	3.4%
uncle/aunt	1	3.4%
other family member	2	6.9%
friend	1	3.4%
Diagnosis:		
lung cancer	5	14.8%
breast cancer	6	22.2%
colon/rectum cancer	1	3.7%
ovarian/uterine cancer	5	18.5%
leukemia	1	3.7%
pancreatic	1	3.7%
Unspecified site	10	33.3%
Average time since diagnosis		
< 1 week	2	6.9%
1-2 weeks	1	3.4%
3-4 weeks	4	13.8%
5-6 weeks	3	10.3%
> 6 weeks	16	55.2%
unspecified	3	10.3%

[a] n=29

Most patients were reported to be fully ambulatory and able to care for themselves, as would be expected of individuals receiving outpatient treatment.

Thirty-eight percent of subjects were males and 62% were females. The majority of subjects were the spouse of the patient (72%) All but one of the remaining 9 subjects was a close relative or family member. That individual was the patient's close friend.

The primary cancer diagnosis was reported by two-thirds of the subjects (n=20). Those occurring with the highest frequencies were breast cancer (n=6), lung cancer (n=5), and ovarian/uterine cancer (n=5). The remaining one-third of subjects simply noted "cancer" as the diagnosis and did not specify a site.

Fifty-five percent (n=16) of the significant others had known the diagnosis for more than six weeks. Ten had received the cancer diagnosis in the preceeding month and one-half. Three individuals did not report the time since diagnosis.

Subjects had completed on average 12.7 years of school. This ranged from a low of completion of the seventh grade to a high of 17 years of schooling.

Subjects were asked to rate on a scale of 1 (strongly agree) to 5 (strongly disagree) their concurrence with following statement: "I prefer to be involved in what is happening to my spouse/relative/friend while he/she is going through radiation therapy". Eighty-three percent (n=24) rated the statement "1", noting very strong agreement. Two individuals rated the statement a 2 (strong agreement) and two others reported an agreement rating of 3 (moderate agreement). The mean of all subjects was 1.2. Twelve subjects viewed the videotape at home and 2 individuals saw the videotape in the hospital setting.

Research Site

The radiation therapy clinic of the University of Massachusetts Medical Center was the site of this study. This clinic had been operational for three years at the commencement of this study and carries a patient load of approximately 60 patients per day. Two linear accelerator treatment machines are employed to deliver the radiation therapy.

Research Staff

A lay research assistant was first hired to coordinate the study. The task included enrolling subjects, administering all written questionnaires, assuring that the intervention was administered in a timely and correct manner and conducting the final interview. The woman hired for this position had worked with oncology patients and, as a staff member of the Oncology Division at the University of Massachusetts Medical Center, had developed a program focused on the needs of individuals going through the grieving process from the loss of a loved one. Through this experience, she gained valuable insight both into patient and family issues and into the protocols and politics of hospital-based provision of care for patients. Due to securing other employment, the Research Assistant resigned after four months of a concerted effort to attend to the study, resulting in the enrollment of five subjects. She did, however, continue to conduct the third week clinic experience interviews with subjects.

Several months after the resignation of the Research Assistant, the nurse who had been the primary promoter of the study within the radiation therapy unit offered to orchestrate the data collection process with the help of the two other clinic nurses. They completed all phases of the study protocol for the remaining 24 subjects.

Measurement Instruments

Two pre- and post-test measurement instruments were used for all subjects:

1. Radiation Therapy Knowledge Assessment

This 16 item questionnaire (see Appendix D) was developed by the researcher using the Cassileth et al. (1982) knowledge assessment instrument as a model. It is comprised of questions which reflect the primary learning objectives of the videotape "Radiation Therapy: A Patient Perspective".

To test for clarity of questions and assess if the instrument would reflect knowledge level differences, a draft of the questionnaire (initially 18 questions) was administered to a convenience sampling of 19 people in the waiting room of the Primary Care Clinic at the University of Massachusetts Medical Center whose responses were thought to generally represent the knowledge level regarding radiation therapy of the population-at-large. These scores were compared to another convenience sampling of 19 patients and family members in the waiting room of the hospital's radiation therapy clinic. The mean score of correctly answered questions for individuals who took the test in the primary care unit waiting room was 6.9 and in all instances, wrong responses were spread across multiple choice alternatives, indicating a balance to question composition. The mean score for correct answers for patients and family members who were actively in the treatment process was 12.3. This anticipated difference in scores indicated the usefulness of the instrument as an indicator of knowledge level regarding radiation therapy.

Informal review of the testing instrument with individuals following completion of the test confirmed that the questions were clear and unambiguous. Two questions were deleted from this final draft after consultation with the radiation therapy nursing staff due to possible confusion in interpretation of the response and redundancy. Content validity was confirmed by the clinic radiation therapist and two members of the nursing staff.

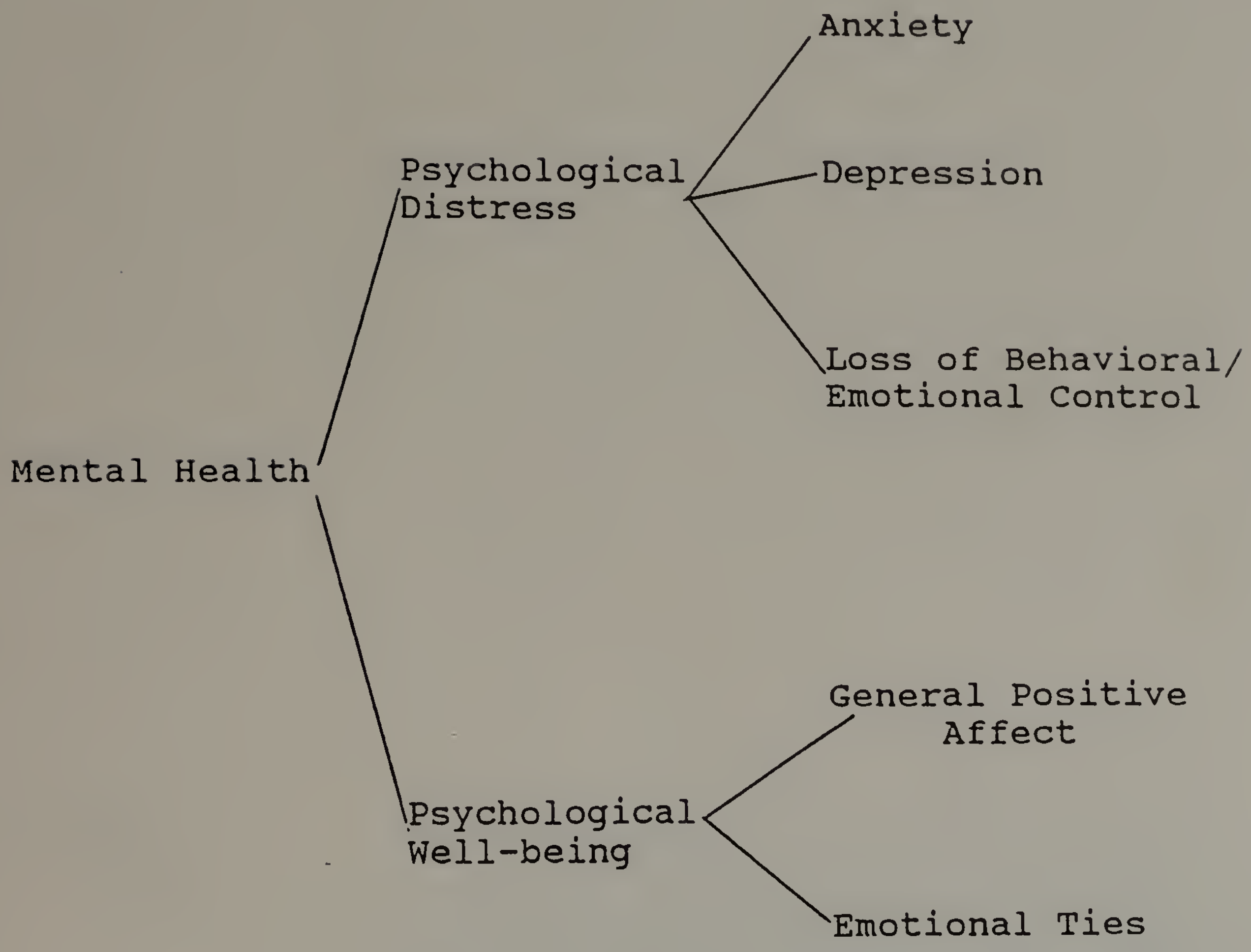
2. Mental Health Inventory

The Mental Health Inventory is a 35 item measure of psychological distress and well-being developed by the Rand Corporation (see Appendix E). The instrument was field tested on 5,089 individuals from the general population. The test can either be analyzed by means of five subscales, each of which is reported to have high internal-consistency reliability ranging from .83 to .91 as measured by Crombach's Coefficient Alpha (Viet and Ware, 1983, p.738) or by two more global indicators of mental health. The subscale indices are: anxiety, depression, loss of behavioral/emotional control, emotional ties and positive affect. The two more global indices are: psychological distress (anxiety, depression, loss of behavioral/emotional control) and psychological well-being (general positive affect and emotional ties) (see Figure 1, p.94).

The data were analyzed according to the five subscales so that the detailed information rendered would provide greater insight into the treatment effect

Figure 1

MHI Subscale Structure



(Ware, 1983, p.3)

and offer a more complete profile of the emotional state of this population.

The videotape treatment group also completed the following instrument:

3. Videotape Assessment

The videotape assessment tool was designed to obtain the subjective opinions of the viewers of the videotape "Radiation Therapy: A Patient Perspective" regarding its content and format. The questionnaire is identical to that of Cassileth et al. (1982) with the addition of three questions: What did you like best about the videotape? What would you suggest be done differently? In what ways did the videotape help you? (see Appendix F).

A convenience sampling of approximately one-half of subjects from each study group participated in the following interview:

4. Clinic Experience Interview

In the third week of the patient's treatment, an outside interviewer conducted a semi-structured interview with a convenience sampling of subjects (Usual group = 9; Videotape group = 8) to assess their perceptions of their experiences in the radiation therapy clinic and of the educational intervention they received (see Appendix G). The first two questions related to the subject's overall satisfaction with the clinic experience. The next three questions asked about the person's perception of the staff. Questions 6 and 7 querried the individual about his or her information needs and information seeking behavior relative to the clinic staff.

General impressions of the videotape were then solicited from the Videotape subjects. They were also asked about the helpfulness of the tape and whether it made it easier or harder to talk with the patient about his or her illness.

Lastly, all subjects were given an opportunity to express any other thoughts about the experience they wished to share.

Treatment of Missing Data

Careful review of the data revealed that a number of subjects from both the Videotape and Usual groups had skipped a question, or in some cases skipped a page of one of the testing instruments. A total of 2 questions were left unanswered in the Knowledge Assessment pretest (Videotape group = 0; Usual group = 2) and 14 questions were left blank on the post-test (Videotape group = 5; Usual group = 9). Unanswered questions on the Knowledge Assessment were coded as missing values and were excluded in the tabluation of means for the correct response analysis.

A total of 7 questions were not completed on the Mental Health Inventory pretest (Videotape group = 1; Usual group = 6). Of the 28 Mental Health Inventory post-tests filled out by subjects, a total of 4 questions were not completed by an individual in the Usual group. Finally, 4 responses to the 1 through 7 rating section on the Videotape Assessment instrument were left blank. Given that the number of unanswered questions was relatively small for both the MHI and Videotape Assessment instrument and fairly evenly distributed over both treatment groups, the variables' mean score of the total subject base (for that pretest or post-test in the case of the MHI) was assigned to these missing values.

Because of the extreme stress one Usual group subject was experiencing at the scheduled time of post-testing, it was deemed to be inappropriate to administer the Mental Health Inventory to this individual. For the purposes of analysis of the MHI, this individual was dropped from the subject base. Therefore, results are based on the data from the 28 subjects (14 Usual Group and 14 Videotape Group) who completed both the pretest and post-test.

Human Subjects Protection

Subjects were introduced to the study during the initial phone call and asked to volunteer for the study during their first visit to the clinic. They could choose not to participate at either of these points, or at any other point during the course of the study. The three nurses and one outside research assistant responsible for implementing the study had worked intensively in the field of oncology and were deemed fully competent to carry out the study design, being respectful of the rights and welfare of study subjects at all times.

The study interventions were not believed to pose a risk to subjects. Although the use of videotapes has not been formally studied with this population in the past, this educational technique is a generally accepted method to meet the informational needs of individuals in the health care system. The usual treatment of subjects was not changed for the Videotape Treatment group, therefore no support or education was withheld from subjects in either of the study conditions. Subjects who were not assigned to the videotape intervention group but who expressed a desire to view the videotape were allowed to do so following the final data gathering session with the subject in the third week.

The research methodology was described in general terms to study subjects at the time informed consent was obtained. An Informed Consent form was thoroughly reviewed and signed by all subjects. All subjects were over the age of 18 and consequently did not need the additional consent of a legal guardian. The clinic nurses were available on an on-going basis to respond to any further questions voiced by subjects.

The privacy and confidentiality of interactions with participants was protected by the three staff nurses involved in conducting the intervention and collecting data, as well as by the researcher and outside research assistant. Subjects' written data were assigned codes for data analysis and all names were removed from the instruments prior to being given to an outside person for the purpose of data entry. Participants will not be identified by name in any reports or publications.

CHAPTER 4

RESULTS

Each of the four ways employed to assess the intervention effect will be reviewed in this chapter. First, the Knowledge Assessment will be analyzed relative to both inter-group and intra-group results. Age, sex and education will be examined to determine any influence these factors may have had on subject responses. The results of the Mental Health Inventory will be presented in a parallel fashion. Subject responses to the clinic experience interviews will then be reviewed. Finally, the data results obtained from the Videotape Assessment will be outlined and factored for age, sex and education influences.

Knowledge Assessment

Knowledge Assessment data were first analyzed to investigate inter-group differences, assessing whether the intervention impacted on subjects' knowledge levels regarding radiation therapy. Intra-group performance trends were then studied to provide further insight into changes in subject responses from the time of pretesting to the time of post-testing. Finally, differences in performance due to the subject's age, sex and education level were examined.

Inter-Group Analysis

Knowledge Assessment responses to the pretest and post-test were analyzed according to whether they were answered correctly or incorrectly. This analysis reflects an accurate assessment of the study effect because it discriminates those who identified the one correct response, indicating their knowledge on the subject, from those who chose the three or four other incorrect choices, indicating a lack of comprehension of the topic. The intervention effect was first computed, followed by a question analysis by group.

Intervention Effect

The correct number of responses on each subject’s pretest and post-test was first tabulated. Incorrect or missing data were excluded from consideration in this analysis. Two-sample t-tests comparing the mean number of correct responses for each subject for each treatment group on both the pretest and post-test were then performed (see Table 3, page 102). The pretest results confirmed that there were no significant differences between the groups at the time of pretesting ($p<.38$, $df=27$) relative to the number of correct and incorrect responses. At the time of post-testing, subjects in the Videotape group performed significantly better than the Usual group subjects ($p<.0005$, $df=27$).

Table 3

COMPARISON OF THE USUAL AND VIDEO TREATMENT GROUPS ON THE KNOWLEDGE ASSESSMENT CORRECT RESPONSE RATE

	Usual Group[a]		Video Group[b]				
	Mean	SD	Mean	SD	*t*	*P*	*DF*
Pretest Performance	5.60	3.11	6.64	3.20	-.89	.38	27
Post-test Performance	9.47	2.07	12.36	1.86	4.0	.0005	27

[a] n=15
[b] n=14

Question Analysis by Group

The answers of each subject on each question of both the pre- and post-test were then coded either 1 for a correct response, 2 for an incorrect response, or 9 for missing data. A mean score for each question for each group was then derived, excluding any missing data. These means were compared using 2-sample t-tests for each question for both the pretest (see Table 4, p.104) and post-test (see Table 5, p.105). This provided further detail about the intervention effect on specific information regarding radiation therapy, as reflected in the content of each question.

No statistical differences were found in question responses between the Usual and Video groups at the time of pretesting. However, statistically significant differences in performance were noted on four of the post-test questions: 2-simulator (p<.02, df=27), 6-time (p<.01, df=26), 9-tumor cells (p<.04, df=27) ,and 10-normal cells (p,.04, df=27). Question 2 asked, "How would you explain a simulator machine?." At the time of post-testing, 93% (n=13) of the Videotape group correctly responded that, "A simulator machine is used to outline the exact area of treatment", while 47% of the Usual subjects reported that they still didn't know or were not sure.

Table 4

GROUP COMPARISON OF
KNOWLEDGE ASSESSMENT PRETEST CORRECT RESPONSE RATE

Pretest Question	Video Group[a] Mean[c]	SD	Usual Group[b] Mean	SD	t	P	DF
1 (friend)	1.1	.27	1.3	.49	1.7	.09	27
2 (simulator)	1.8	.43	1.7	.47	-.42	.68	26
3 (treatment)	1.8	.43	1.8	.43	.00	1.0	26
4 (radioactive)	1.1	.36	1.3	.46	.80	.43	27
5 (lead blocks)	1.4	.51	1.6	.51	.74	.47	26
6 (time)	1.9	.36	1.9	.35	.07	.94	27
7 (stomach)	1.4	.51	1.5	.52	.20	.84	27
8 (painful)	1.2	.43	1.4	.51	1.06	.30	27
9 (tumor cells)	1.6	.51	1.9	.35	-1.79	.09	27
10 (normal cell)	1.6	.50	1.8	.41	.92	.36	27
11 (marks)	2.0	.00	1.9	.26	-1.0	.34	27
12 (side effect)	1.6	.51	1.7	.46	.90	.38	27
13 (external)	1.9	.36	2.0	.00	1.53	.14	27
14 (seen/heard)	1.7	.47	1.7	.49	-.27	.79	27
15 (working)	1.5	.52	1.5	.52	.17	.86	27
16 (weeks)	1.6	.50	1.5	.52	-93	.36	27

[a] n=15
[b] n=14
[c] 1=correct; 2=incorrect

Table 5

GROUP COMPARISON OF KNOWLEDGE ASSESSMENT POST-TEST CORRECT RESPONSE RATE

Post-test Question	**Video Group**[a]		**Usual Group**[b]		*t*	*p*	DF
	Mean[c]	SD	Mean	SD			
1 (friend)	1.0	.00	1.1	.26	.96	.34	27
2 (simulator)	1.1	.27	1.5	.52	2.6	.02*	27
3 (treatment)	1.6	.51	1.5	.52	-.20	.84	27
4 (radioactive)	1.1	.28	1.1	.26	-.10	.92	26
5 (lead blocks)	1.0	.00	1.1	.36	1.42	.17	25
6 (time)	1.3	.48	1.8	.41	2.9	.01*	26
7 (stomach)	1.1	.27	1.3	.46	1.4	.18	27
8 (painful)	1.0	.00	1.1	.26	.96	.34	27
9 (tumor cells)	1.1	.27	1.4	.51	2.2	.04*	27
10 (normal cell)	1.1	.27	1.4	.51	2.2	.04*	27
11 (marks)	1.5	.52	1.6	.51	.58	.56	25
12 (side effect)	1.2	.43	1.5	.52	1.4	.19	25
13 (external)	1.8	.43	1.9	.29	.90	.38	24
14 (seen/heard)	1.1	.36	1.3	.48	1.0	.32	25
15 (working)	1.1	.28	1.3	.49	1.7	.11	26
16 (weeks)	1.4	.51	1.4	.51	.08	.94	26

[a] n=15
[b] n=14
[c] 1=correct; 2=incorrect
* $p<.05$

The correct response to question 6, "The average length of time radiation is being delivered during the treatment:" was "30 to 90 seconds". When post-tested, only 20% of the Usual subjects (n=3) responded correctly, and 47% (n=7) still did not know or were not sure. In comparison, 64% (n=9) of the Videotape group subjects knew the actual length of treatment.

Questions 9 and 10 tested the individual's understanding of the way radiation therapy affects cells, reflecting comprehension of one of the basic principles of the treatment process. Specifically, question 9 asks about the affect of therapy on tumor cells. Response choices were that tumor cells: A. are able to repair themselves after being damaged by radiation therapy B. are not easily damaged by radiation therapy C. are not able to repair themselves after being damaged by radiation therapy and D. don't know/not sure. Ninety-three percent (n=13) of the Videotape subjects knew that tumor cells are not able to repair themselves after being damaged by radiation therapy at post-testing while only 60% (n=9) of the Usual subjects were aware of this fact.

Similarly, question 10 asks about the attributes of normal cells damaged by radiation therapy. Again, ninety-three percent (n=13) of Videotape subjects as compared to 60% (n=9) of the Usual subjects knew that normal cells were able to repair themselves after being damaged by radiation therapy.

No significant differences were found between groups in performance on the remaining 12 questions, however, Videotape subjects out-performed Usual subjects relative to correct answers on all but 3 questions at the time of post-testing. They responded correctly only slightly less frequently to question 3 ("If your friend asked what radiation treatment does, would you say:"), and correctly responded with equal frequency to questions 4 ("If someone said,'People who get external radiotherapy become radioactive to others,' what would you reply?") and 16 ("A course of radiaiton therapy treatment lasts five days a week for:) (see Table 5, p.105).

Intra-Group Analysis

Changes in correct response performance of each treatment group from the time of pretesting to the time of post-testing were then analyzed. As previously noted, knowledge question data were coded according to correct (equals 1) and incorrect (equals 2) responses. Changes in the mean correct response rate from the pre- to post-test for each question was then ascertained by use of a series of 1 sample t-tests for both the Usual and Videotape groups (see Tables 6 and 7, pages 108 and 109 respectively). These analyses offered insight

Table 6

THE FREQUENCIES OF KNOWLEDGE ASSESSMENT CORRECT RESPONSES OF THE USUAL GROUP ON PRE- AND POST-TESTS[a]

Question	**Pretest**		**Post-test**				
	Mean[b]	SD	Mean	SD	t	P	DF
1 (friend)	1.3	.49	1.1	.26	-2.26	.04*	14
2 (simulator)	1.7	.47	1.5	.52	-1.88	.08	13
3 (treatment)	1.8	.46	1.5	.52	-1.87	.08	13
4 (radioactive)	1.3	.46	1.1	.26	-1.87	.08	14
5 (lead blocks)	1.6	.51	1.1	.36	-3.12	.008**	14
6 (time)	1.9	.35	1.8	.41	-1.0	.33	14
7 (stomach)	1.5	.52	1.3	.46	-1.87	.08	14
8 (painful)	1.4	.51	1.1	.26	-2.65	.02*	14
9 (tumor cells)	1.9	.35	1.4	.51	-3.50	.004**	14
10 (normal cells)	1.8	.41	1.4	.51	-3.06	.009**	14
11 (marks)	1.9	.26	1.6	.51	-2.31	.04*	12
12 (side effect)	1.7	.46	1.4	.51	-2.31	.04*	12
13 (external)	2.0	.00	1.9	.29	-1.00	.34	11
14 (seen/heard)	1.7	.49	1.3	.48	-3.21	.008**	12
15 (working)	1.5	.52	1.3	.49	-1.87	.08	14
16 (weeks)	1.5	.52	1.4	.51	-1.00	.33	14

[a] n=15
[b] 1=correct; 2=incorrect

* $p<.05$
** $p<.01$

Table 7

THE FREQUENCIES OF KNOWLEDGE ASSESSMENT CORRECT RESPONSES OF THE VIDEOTAPE GROUP ON PRE- AND POST-TESTS[a]

Question	Pretest		Post-test				
	Mean[b]	SD	Mean	SD	t	P	DF
1 (friend)	1.1	.27	1.0	.00	-1.00	.34	13
2 (simulator)	1.8	.43	1.1	.27	-5.70	.0001***	13
3 (treatment)	1.8	.43	1.6	.51	-1.88	.08	13
4 (radioactive)	1.1	.36	1.1	.28	.00	1.0	12
5 (lead blocks)	1.4	.51	1.0	.00	-2.74	.02*	12
6 (time)	1.9	.36	1.3	.48	-3.74	.003**	12
7 (stomach)	1.4	.51	1.1	.27	-2.69	.02*	13
8 (painful)	1.2	.43	1.0	.00	-1.88	.08	13
9 (tumor cells)	1.6	.51	1.1	.27	-3.61	.003**	13
10 (normal cells)	1.6	.50	1.1	.27	-4.16	.001***	13
11 (marks)	2.0	.00	1.5	.52	-3.61	.003**	13
12 (side effect)	1.6	.51	1.2	.43	-2.69	.02*	13
13 (external)	1.9	.36	1.8	.43	-1.00	.34	13
14 (seen/heard)	1.7	.47	1.1	.36	-4.16	.001***	13
15 (working)	1.5	.52	1.1	.28	-2.74	.02*	12
16 (weeks)	1.6	.50	1.3	.48	-2.31	.04*	12

[a] n=14
[b] 1=correct; 2=incorrect
* $p<.05$
** $p<.01$
*** $p<.001$

into the exact nature of the changes of each study group at these two points in time.

The Usual group demonstrated significant improvement in their correct response rate on 8 questions from the time of pretesting to post-testing (see Table 6, page 108). Four of these questions had a significance level of $p<.05$ (1-friend, 8-painful, 11-marks and 12-side effect) and the remaining four reached a significance of $p<.01$ (5-lead blocks, 9-tumor cells, 10-normal cells and 14-seen/ heard). No statistically significant improvement occurred on 8 questions.

Significant improvement in the correct response rate was evident on 11 of the questions answered by Videotape subjects (see Table 7, page 109). The level of significance was $p<.05$ on 5 of these questions (5-lead blocks, 7-stomach, 12-side effects, 15-working, 16-weeks) and $p<.01$ on 3 of the questions (6-time, 9-tumor cells, 11-marks). The remaining three questions where improvement was made reached a highly significant level of $p<.001$ (2-simulator, 10-normal cells, and 14-seen/heard). No statistically significant improvement was demonstrated on 5 questions.

Influence of Subject Sex, Age and Education

To discern whether the subjects' sex, age or educational level may have influenced the nature of Knowledge Assessment responses, an analysis of variance test was performed for each question by each of these three factors. For this purpose, the means of all subject (n=29) responses to each question on both the pretest and post-test were employed.

Sex

The sex of the subject did not significantly affect the response choice to questions, as answer differences between males and females did not differ beyond that which would be expected by chance.

Age

The age of the subject was delineated into one of six age intervals: less than 30 (n=2), 30 to 39 years (n=1), 40 to 49 years (n=6), 50 to 59 years (n=4), 60 to 69 years (n=9) and 70 years or older (n=7). The age of the subject also did not influence the response to questions as differences between these age categories fell within that which would be expected by chance.

Educational Level

The last year of school completed by subjects was coded into 3 categories: ninth grade or below (n=3), grades 10 through 12 (n=13) and grades 13 and above (n=13). Once again, the educational experience of subjects did not affect their responses to the Knowledge Assessment. Performance differences between these education categories were within the bounds of what would be expected by chance.

Summary

An analysis of variance performed on each pretest and post-test question revealed no pattern of influence of the age, sex or educational experience of subjects on question responses. However, it is important to consider that this factor analysis may have been affected by the low subject numbers in the differing age and educational categories. The effect of the subjects' age, sex and education experience on knowledge performance warrants further attention in future studies where a larger sample population is available.

General Observations

This correct response comparison provides interesting insight into what information subjects initially lacked, and what knowledge was not gained in either group.

The question receiving the fewest correct responses on both the pre- and post-test (7% and 14% respectively) was regarding the three possible uses of external radiation therapy (see question 13, Tables 6 and 7, pages 108 and 109 respectively). Response choices offered were: A. kill tumor cells B. shrink large tumors C. relieve pain D. all of the above (correct choice) and E. Don't know/not sure. At the time of the post-test, 52 percent responded that it was used to kill tumor cells only, 10 percent said that it was only used to shrink large tumors, and 24 percent noted that they didn't know or weren't sure. Only 14 % of respondents (n=4) knew that external radiation therapy was regularly used for all three purposes.

The responses may have reflected the reasons for which the subjects' significant others were being treated, this being foremost in the individual's mind as the use for radiation therapy. This possibility is further supported by the fact that no subjects noted the use of treatment for pain relief. Given that palliative patients were for the most part excluded from the study, it would be anticipated that this use of therapy would not be identified by the study population.

A second question which subjects did poorly on in both testing sessions was regarding the nature of the marks which are put on the patient's skin to identify the treatment area (see question 11, Tables 6 and 7, pages 108 and 109 respectively). Subjects were given the following response choices about the type of marks made: 1. large and permanent 2. small and permanent 3. are not permanent 4. don't know/not sure. At the time of the pretest, only 1 subject (3%) noted the right answer of "small and permanent". Fifty-two percent (n=15) thought that they were not permanent and 45% (n=13) did not know or weren't sure. On post-testing, 12 individuals (41%) had the correct response, 10 (34%) still thought that the marks were not permanent and 7 (24%) were still not sure. The poor post-test performance on this question is surprising both because this fact is stressed by the physician in the initial meeting and it is reinforced when the patient is marked during the simulation visit. Although the marks are extremely small and difficult to see, responses may reflect denial on the part of the patient and family members to acknowledge their permanent existence, an ever-present reminder of the cancer.

Although a significant difference was noted in the correct response rate between the Usual and Videotape groups on the question regarding the average length of time radiation is delivered during the treatment, performance on this question was generally poor (see question 6, Tables 6 and 7, pages 108 and 109 respectively). Only 12 (41%) of subjects answered the question correctly on the post-test. Answer options were as follows: A. 30 to 90 seconds B. 3 to 7 minutes C. 10 to 15 minutes D. 15 to 20 minutes E. Don't know/not sure. Answer "A", 30 to 90 seconds was the correct response. As previously noted, at the time of post-testing, 3 (20%) of the Usual subjects gave the right answer, while 9 (64%) of the videotape subjects followed suit.

Again, this is a surprising outcome, particularly for the videotape group who saw an actual treatment being delivered on the film. Despite the seeming clarity of the question, it may have been that respondents interpreted it to be asking how long it took the patient to both be set-up for treatment and then actually treated.

Another unexpected post-test score was on the third question: "If your friend asked what radiation treatment does, would you say: A. It destroys most cells it passes through B. It destroys the largest cells it hits. C. It destroys mainly tumor cells. or D. Don't know/not sure" (see question 3, Tables 6 and 7, pages 108 and 109 respectively). Twelve subjects (Usual group = 7 (47%); Videotape group = 6 (43%)), knew that the therapy destroys mainly tumor cells. The process of the therapy generally protects the other cells it passes through from damage. Despite this fact being reviewed by the physician in the intial meeting and highlighted on the videotape, 48% (n=14) of the subjects thought that the treatment destroyed most cells it passed through at the time of post-testing. This is a difficult concept to understand and appears to require greater attention by the clinic staff in any educational sessions with the patient and family members.

A fairly common concern expressed by patients and family members is whether the individual being treated will become radioactive in the process. Although 79% of subjects (n=23) knew at the time of the pretest that patients receiving external radiotherapy will not become radioactive, 21% (n=6) were not sure about this fact. At the time of the post-test, two individuals still remained unsure (7%) and one respondents (3%) thought that, "Patients become a little radioactive and may be harmful to others". Again, it is important that this misconception be dispelled by the staff as early as possible in the treatment process. Lack of doing so may lead to the patient being isolated from friends and family for fear of transmission of radioactivity.

Further analysis of pretest responses offers a sense of some of the other questions and misinformation subjects carried with them to their first visit to the clinic. At the time of the pretest, 28% (n=8) were not sure if the actual treatment itself caused pain and 1 individual responded that it did cause pain but just in the treatment area. When asked to identify the side effect(s) of treatment most patients will experience (choices: diarrhea, vomiting, tiredness, or all three), 14% noted that all three would occur and 55% did not know. Finally, 4 subjects (14%) reported that very few patients continue working when going through a course or radiation therapy and 38% were unsure about this possibility.

Conversely, subjects did demonstrate some basic knowledge about radiation therapy treatment at the time of pretesting. Seventy-nine percent (n=23) knew that radiation therapy is given to a particular spot in the patient's body rather than being a systemic treatment such as chemotherapy. A comparable number of individuals knew that the patient would not become radioactive. Twenty subjects (69%) were not afraid that the treatment would be painful. Slightly over half of the respondents correctly noted the use of the lead blocks to protect untreated body parts (52%) and reasoned that an individual having treatment to the stomach would most likely have a localized side effect (nausea) (55%).

Summary

The Knowledge Assessment results revealed that the Videotape group performed significantly better than did the Usual group (p<.0005, df=27). This fact indicates that the videotape did have an effect on subject knowledge levels regarding radiation therapy. The sex, age or educational level of subjects did not influence their performance. The Knowledge Assessment instrument also served as a valuable tool to identify areas of educational need for this population.

Mental Health Inventory

The Rand Corporation Mental Health Inventory (MHI) was administered to subjects at the time of enrollment in the study and during the third week of the patient's treatment. One subject from the Usual group was unable to complete the MHI post-test and therefore the data analysis was performed on information from the 28 completed subject files. A number of subjects did skip one or several questions. As previously mentioned, the mean score for the total group was assigned to the 7 pretest and four post-test questions where responses were not noted.

MHI questions were grouped according to the following five subscales which reflected the subjects' mental health status at the time of testing: anxiety, depression, loss of behavioral/emotional control, general positive affect and emotional ties.

The MHI data were first analyzed to study intergroup differences, assessing whether or not the intervention impacted on the subjects' state of emotional health. Intra-goup response trends were studied to further discern any change patterns. Finally, differences in subscale responses due to the subjects' age, sex or education level were examined.

Inter-Group Analysis

The sum of each subject's subscale responses were first calculated. The mean scores for each of these subscales for both study groups at the time of the pretest and post-test were then compared by 2-sample t-tests (see Tables 8 and 9, pages 120 and 121 respectively). No significant differences between Videotape and Usual subjects were found at the time of either testing session.

Intra-Group Analysis

Again, the sum of each subject's subscale responses were first calculated. The mean performance of each group on each subscale was then analyzed using of a series of one-sample t-tests to discern whether Usual and/or Videotape Treatment subject performance changed from the time of pretesting to post-testing (see Tables 10 and 11, pages 122 and 123 respectively). The study groups did not significantly change their responses to the Mental Health Inventory questions at these two testing sessions.

Influence of Subject Sex, Age and Education:

To discern whether the subjects' sex, age or educational level influenced the nature of their responses on the MHI, an analysis of variance was performed for each pretest (n=35) and post-test (n=35) question for each of these factors.

Sex

The gender of the subjects did not affect their responses on any of the five subscale indices, as performance did not differ between the sexes beyond that expected by chance.

Table 8

MHI PRETEST SUBSCALE COMPARISON BY STUDY GROUP

Subscale	Usual[a]		Video[b]		t	P	DF
	Mean	SD	Mean	SD			
Anxiety	44.9	5.6	45.9	6.4	-.41	.69	26
Depression	19.0	2.0	19.0	2.2	.00	1.0	26
Loss Control	31.7	2.7	31.6	1.1	.11	.92	26
Pos. Affect	28.1	12.0	27.2	9.8	.21	.84	26
Emot. Ties	8.6	2.0	8.2	1.6	.52	.61	26

[a] n=14
[b] n=14

Table 9

MHI POST-TEST SUBSCALE COMPARISON BY STUDY GROUP

Subscale	Usual[a]		Video[b]		t	P	DF
	Mean	SD	Mean	SD			
Anxiety	45.8	6.5	46.4	6.2	-.24	.82	26
Depression	19.1	3.2	19.4	2.2	-.28	.78	26
Loss Control	31.4	1.5	32.0	1.7	-.97	.34	26
Pos. Affect	27.1	12.0	24.4	10.1	.65	.52	26
Emot. Ties	9.1	2.6	8.1	1.6	1.2	.23	26

[a] n=14

[b] n=14

Table 10

USUAL GROUP[a] MHI PRE- TO POST-TEST SUBSCALE COMPARISON

Subscale	Pretest Mean	Pretest SD	Post-test Mean	Post-test SD	*t*	*P*	DF
Anxiety	44.9	5.6	45.8	6.5	-1.0	.34	13
Depression	19.0	2.0	19.1	3.2	-.01	.92	13
Loss Control	31.7	2.3	31.4	1.5	.50	.62	13
Pos. Affect	28.1	12.0	27.1	11.9	.68	.51	13
Emot. Ties	8.6	2.0	9.1	2.6	-.86	.41	13

[a] n=14

Table 11

VIDEOTAPE GROUP MHI PRE- TO POST-TEST SUBSCALE COMPARISON

Subscale	Pretest[a]		Post-test[b]		t	P	DF
	Mean	SD	Mean	SD			
Anxiety	45.9	6.4	46.4	6.2	-.67	.52	13
Depression	19.0	2.2	19.4	2.2	-.81	.43	13
Loss Cont.	31.6	1.1	32.0	1.6	-1.1	.29	13
Pos. Affect	27.2	9.8	24.4	10.1	1.9	.08	13
Emot. Ties	8.2	1.6	8.1	1.6	.32	.75	13

[a] n=14
[b] n=14

Age

The ages of subjects were categorized into one of six age intervals: less than 30 (n=2), 30 to 39 years (n=1), 40 to 49 years (n=5), 50 to 59 years (n=4), 60 to 69 years (n=9) and 70 years of age or older (n=7). Again, the analyses of variance revealed that this factor did not impact on the nature of the subscale responses on either pretest or post-test questions beyond differences between age categories which would be expected to be found by chance.

Educational Level

The last year of school completed by subjects was delimited into three categories: ninth grade or below (n=3), grades 10 through 12 (n=13) and grades 13 and above (n=12). The educational experience of subjects did significantly affect their responses to 3 questions on the MHI pretest (see Table 12, page 125) and 3 questions on the Post-test (see Table 13, page 129).

The first pretest question impacted by educational experience related to the subject's level of satisfaction with his or her personal life (see Table 14, question 1, page 134). Individuals having completed no more than 9 years of schooling (n=3) were dissatisfied and unhappy with their personal lives. The remaining subjects reported being generally satisfied with their lives in the past month.

Table 12

THE INFLUENCE OF EDUCATION ON MHI PRETEST RESPONSES

Quest.	Educ. Level	Mean	Sum of Squares		DF		F	P
			Among	Within	Among	Within		
1	a	5.7	18.5	54.0	2	25	4.3	.03*
	b	3.0						
	c	3.1						
2	a	2.7	4.8	28.7	2	25	2.1	.15
	b	4.0						
	c	4.0						
3	a	3.0	.36	58.4	2	25	.08	.93
	b	2.8						
	c	2.7						
4	a	3.0	4.0	47.7	2	25	1.1	.36
	b	3.7						
	c	2.9						
5	a	4.0	.52	63.6	2	25	.10	.90
	b	3.9						
	c	3.7						
6	a	3.0	3.2	55.5	2	25	.72	.50
	b	3.5						
	c	2.8						
7	a	1.7	.22	19.0	2	25	.15	.86
	b	1.8						
	c	1.7						
8	a	4.0	.02	7.8	2	25	.03	.97
	b	4.1						
	c	4.1						
9	a	2.3	7.5	29.2	2	25	3.2	.06
	b	1.2						
	c	2.3						
10	a	3.7	3.3	31.4	2	25	1.3	.29
	b	4.6						
	c	4.8						

Continued next page

Table 12 continued:

Quest.	Educ. Level	Mean	Sum of Squares		DF		F	P
			Among	Within	Among	Within		
11	a	3.7	2.3	50.4	2	25	.58	.57
	b	2.7						
	c	2.9						
12	a	3.7	1.6	26.8	2	25	.75	.48
	b	4.5						
	c	4.4						
13	a	1.3	1.4	14.5	2	25	1.2	.33
	b	2.1						
	c	1.9						
14	a	5.0	1.1	15.9	2	25	.84	.44
	b	5.5						
	c	5.7						
15	a	5.7	2.1	18.6	2	25	1.4	.27
	b	4.8						
	c	5.3						
16	a	3.3	.58	39.3	2	25	.19	.83
	b	3.2						
	c	2.9						
17	a	2.7	.61	35.1	2	25	.22	.81
	b	2.3						
	c	2.2						
18	a	4.7	.45	17.0	2	25	.33	.72
	b	4.8						
	c	5.0						
19	a	3.7	3.0	21.6	2	25	1.8	.19
	b	4.8						
	c	4.7						
20	a	6.0	.16	1.7	2	25	1.2	.31
	b	5.8						
	c	6.0						
21	a	3.0	4.8	39.0	2	25	1.5	.23
	b	1.7						
	c	2.3						

Continued next page

Table 12 continued:

Quest.	Educ. Level	Mean	Sum of Squares		DF		F	P
			Among	Within	Among	Within		
22	a	3.7	4.3	36.7	2	25	1.5	.25
	b	4.4						
	c	4.9						
23	a	3.3	6.2	25.9	2	25	3.0	.07
	b	4.8						
	c	4.9						
24	a	3.0	.07	68.6	2	25	.01	.99
	b	2.8						
	c	2.9						
25	a	4.7	2.6	31.3	2	25	1.0	.37
	b	4.8						
	c	5.4						
26	a	5.0						
	b	5.0		no variance				
	c	5.0						
27	a	4.0	7.5	19.7	2	25	4.8	.02*
	b	4.4						
	c	5.3						
28	a	5.3	.03	13.2	2	25	.02	.98
	b	5.2						
	c	5.3						
29	a	3.0	.63	43.5	2	25	.18	.84
	b	3.5						
	c	3.3						
30	a	4.7	.86	16.0	2	25	.67	.52
	b	4.4						
	c	4.8						
31	a	2.3	11.7	28.4	2	25	5.2	.01*
	b	4.3						
	c	4.5						
32	a	2.7	1.4	44.6	2	25	.38	.69
	b	3.2						
	c	2.8						

Continued next page

Table 12 continued:

Quest.	Educ. Level	Mean	Sum of Squares		DF		F	P
			Among	Within	Among	Within		
33	a	4.7	.63	20.3	2	25	.39	.68
	b	5.0						
	c	5.2						
34	a	4.3	2.7	13.4	2	25	2.5	.10
	b	4.6						
	c	5.2						
35	a	4.7	6.4	45.3	2	25	1.8	.19
	b	3.2						
	c	3.1						

a = 9th grade or below; n=3
b = grades 10 through 12; n=13
c = grades 13 and above; n=12

Table 13

THE INFLUENCE OF EDUCATION ON MHI POST-TEST RESPONSES

Quest.	Educ. Level	Mean	Sum of Squares		DF		F	P
			Among	Within	Among	Within		
1	a	2.0	1.2	17.4	2	25	.89	.42
	b	2.7						
	c	2.7						
2	a	2.7	7.3	36.1	2	25	2.5	.10
	b	3.7						
	c	4.3						
3	a	3.0	5.5	44.6	2	25	1.5	.23
	b	3.1						
	c	2.2						
4	a	2.7	.60	47.3	2	25	.16	.85
	b	3.1						
	c	2.8						
5	a	3.7	4.1	36.4	2	25	1.4	.26
	b	3.7						
	c	2.9						
6	a	2.7	1.7	31.0	2	25	.67	.52
	b	2.8						
	c	2.3						
7	a	1.3	.97	21.9	2	25	.55	.58
	b	1.8						
	c	1.4						
8	a	4.0	.07	9.4	2	25	.09	.91
	b	4.2						
	c	4.2						
9	a	2.7	4.6	36.8	2	25	1.6	.23
	b	1.5						
	c	2.0						
10	a	3.3	7.4	26.7	2	25	3.5	.05*
	b	4.6						
	c	5.1						

Continued next page

Table 13 continued:

Quest.	Educ. Level	Mean	Sum of Squares Among	Sum of Squares Within	DF Among	DF Within	F	P
11	a	2.6	.22	53.9	2	25	.05	.95
	b	2.8						
	c	2.6						
12	a	3.3	5.4	23.6	2	25	2.9	.08
	b	4.5						
	c	4.8						
13	a	1.7	.22	9.0	2	25	.31	.74
	b	1.8						
	c	1.7						
14	a	5.0	1.7	8.7	2	25	2.4	.11
	b	5.6						
	c	5.8						
15	a	4.3	4.2	20.5	2	25	2.6	.10
	b	5.1						
	c	5.6						
16	a	2.7	2.1	34.6	2	25	.77	.47
	b	3.1						
	c	2.5						
17	a	2.3	.46	26.5	2	25	.22	.81
	b	1.9						
	c	1.9						
18	a	4.7	.94	14.0	2	25	.84	.45
	b	4.8						
	c	5.2						
19	a	5.0	.37	22.6	2	25	.21	.81
	b	4.9						
	c	5.2						
20	a	6.0	.04	.92	2	25	.56	.58
	b	5.9						
	c	6.0						
21	a	2.7	.85	61.3	2	25	.17	.84
	b	2.1						
	c	2.2						

Continued next page

Table 13 continued:

Quest.	Educ. Level	Mean	Sum of Squares		DF		F	P
			Among	Within	Among	Within		
22	a	4.7	.55	28.4	2	25	.24	.79
	b	4.4						
	c	4.7						
23	a	3.7	7.0	19.6	2	25	4.5	.02*
	b	5.2						
	c	5.3						
24	a	2.7	3.0	82.7	2	25	.05	.96
	b	3.0						
	c	3.0						
25	a	5.0	1.7	29.0	2	25	.74	.49
	b	5.0						
	c	5.5						
26	a	5.0						
	b	5.0	no variance					
	c	5.0						
27	a	3.3	8.9	27.6	2	25	4.0	.03*
	b	4.5						
	c	5.2						
28	a	5.0	.23	17.0	2	25	.17	.85
	b	5.3						
	c	5.3						
29	a	3.0	.36	54.4	2	25	.08	.92
	b	3.2						
	c	3.3						
30	a	4.7	.90	14.8	2	25	.76	.48
	b	4.5						
	c	4.9						
31	a	4.0	1.9	39.0	2	25	.62	.54
	b	4.3						
	c	4.8						
32	a	2.7	.27	43.8	2	25	.08	.93
	b	2.9						
	c	2.8						

Continued next page

Table 13 continued:

Quest.	Educ. Level	Mean	Sum of Squares Among	Sum of Squares Within	DF Among	DF Within	F	P
33	a	5.3	2.2	19.6	2	25	1.4	.26
	b	4.8						
	c	5.3						
34	a	4.0	3.5	30.0	2	25	1.4	.26
	b	4.8						
	c	5.2						
35	a	3.7	1.7	51.3	2	25	.42	.66
	b	3.1						
	c	2.8						

a = 9th grade or below; n=3
b = grades 10 through 12; n=13
c = grades 13 and above; n=12

The second pretest question influenced by the subjects' education asked about their degree of restlessness over the past month (see Table 14, question 27, page 134). Individuals having completed 12 years of schooling or less (n=13) generally felt that they were "restless, fidgety or impatient" some of the time. Subjects who had pursued schooling beyond high school reported that they experienced these symptoms only "a little of the time".

Finally, the last pretest question demonstrating significance asked the respondents to identify their degree of anxiousness over the past month (see Table 14, question 31, page 134). Subjects with a ninth grade education or less (n=3) reported that they were "very much" anxious or worried over this time interval. Those having complete greater than 10 years of schooling generally reported only "some" anxiousness or worry in their lives.

Three questions in the post-test results were influenced by the subjects' education. The first question querried respondents about the amount of time in the last month they had been "a very nervous person" (see Table 15, question 10, page 135). Individuals with a ninth grade education or less (n=3) reported being very nervous a good bit of the time. Those who completed high school (n=13) were very nervous a little to some of

Table 14

QUESTION ANALYSIS OF MHI PRETEST RESPONSES INFLUENCED BY EDUCATION[a]

1. How happy, satisfied or pleased have you been with your personal life in the past month?

Response Choices	Mean
1. Extremely happy	
2. Very happy most of the time	≤9 years = 5.7
3. Generally satisfied, pleased	
4. Sometimes fairly satisfied, sometimes fairly unhappy	10-12 years = 3.0
5. Generally dissatisfied, unhappy	13+ years = 3.1
6. Very dissatisfied, unhappy most of the time	

27. During the past month, how much of the time have you felt restless, fidgety or impatient?

Response Choices	Mean
1. All of the time	
2. Most of the time	≤9 years = 4.0
3. A good bit of the time	
4. Some of the time	10-12 years = 4.4
5. A little of the time	
6. None of the time	13+ years = 5.3

31. During the past month, have you been anxious or worried?

Response Choices	Mean
1. Yes, extremely so	
2. Yes, very much so	≤9 years = 2.3
3. Yes, quite a bit	
4. Yes, some, enough to bother me	10-12 years = 4.3
5. Yes, a bit	
6. No, not at all	13+ years = 4.5

---

[a] n=3 ≤ 9 yrs.; n=13 10-12 yrs.; n=12 13+ yrs.

Table 15

QUESTION ANALYSIS OF MHI POST-TEST RESPONSES INFLUENCED BY EDUCATION[a]

10. How much of the time during the past month have you been a very nervous person?

Response Choices

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

Mean

≤9 years = 3.3
10-12 years = 4.6
13+ years = 5.1

23. How much have you been bothered by nervousness or your "nerves" during the past month?

Response Choices

1. Extremely so
2. Very much bothered
3. Bothered quite a bit by nerves
4. Bothered some, enough to notice
5. Bothered just a little by nerves
6. Not bothered at all by this

Mean

≤9 years = 3.7
10-12 years = 5.2
13+ years = 5.3

27. During the past month, how much of the time have you felt restless, fidgety, or impatient?

Response Choices

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

Mean

≤9 years = 3.3
10-12 years = 4.5
13+ years = 5.2

---

[a] n=3 ≤ 9 yrs.; n=13 10-12 yrs.; n=12 13+ yrs.

the time. Subjects having 13 or greater years of education were the least nervous, reporting the occurrence of nervousness only a little of the time.

The second question was very similar to the one noted above, asking the subjects how often they had been bothered by their nervousness (see Table 15, question 23, page 135). A similar pattern of response emerges, with the subjects having the least educational experience being bothered more by their nervousness than the better educated individuals. This is a logical response in that individuals reporting greater nervousness would be expected to be more bothered by its presence than individuals reporting a minimal amount of nervous behavior.

Question 27 was the only question influenced by educational level on both the pretest and post-test. Subjects with nine years of schooling or less again reported being the most restless, fidgety and impatient (see Table 15, page 135). The occurrence of these feelings actually increased from the time of pretesting. Individuals in the upper level education categories reported a lesser occurrence of these attributes, noting that restless qualities were present on average only a "little of the time".

Summary

The sex and age of subjects did not significantly affect their responses to the MHI. However, the education level of individuals did reveal a pattern of influence. Subjects with lower education levels reported experiencing less satisfaction with their lives than did those individuals with greater educational experience, as witnessed by reports of higher levels of restlessness, nervousness and worry. Caution should be taken in generalizing these findings given the limited subject base (n=3) in the lowest education group.

Clinic Experience Interview

A convenience sampling of 9 subjects from the Usual Treatment group and 8 subjects from the Videotape Treatment group participated in a semi-structured interview with a non-staff interviewer. These interviews were audiotaped and transcribed. A summary of the subjects' comments can be found in Appendix J.

Level of Satisfaction

In general, subjects from both the Usual and Videotape groups were very satisfied with their experiences in the clinic. When asked to rate their satisfaction on a scale of 1 to 10 (1 being not at all satisfied and 10 being very, very satisfied), the Usual group reported an average rating of 9.33 while the Videotape group averaged 9.37.

Staff Competence

Staff competence appears central to this positive assessment. The staff consistently received rave reviews from subjects. A sampling of the staff descriptors was as follows: "Everyone is very nice and understanding", "I think that they are caring, and this is without exception", "They are all capable, responsive to the patient's needs.", "They are very helpful and very cheerful and willing to help you the minute you come in" and, "They seem very efficient and they make you feel good". Subjects did not express any areas in which the radiation therapy staff could have been more helpful or tell of things which had been done which were not helpful. The only negative comments about the experience were in reference to waiting at the registration area when patients first arrive at the hospital, and one instance when the van did not pickup a patient due to bad weather.

All subjects reported being able to readily obtain information they wanted to know about the patients' treatment. When asked to identify the person they would go to to seek information about treatment, six subjects in the Usual group identified a nursing staff member, and three suggested the specialist who referred them to the clinic. In the Videotape group, only two subjects identified a nursing staff member, five individuals noted that they would go directly to the radiation oncologist, and one reported going to a friend who had a medical background (see Table 16, page 140).

It is important to note that regardless of the staff member first identified as the one to answer a question, all but one subject who was interviewed cited ready access to both the nursing and physician staff. Doing independent reading was also noted by several subjects as an effective means to have informational needs met, although one individual vocalized that this can be a difficult task at times: "It is sometimes hard to pick up a book and read, you know, just read information about it".

Videotape Group Feedback

The Videotape Treatment group members were asked about their reactions to the videotape: Was it helpful? If so, in what ways? Was it not helpful? If so, why not? All subjects in this group reported that the videotape was helpful. The following comments typify the responses: ""Excellent tape", "Very informative", "I had never had any contact with cancer before and I enjoyed the tape", "I felt that my mind was more at ease" (after videotape viewing), "I mean I didn't really know how to accept this to begin with and (it) answered a lot of thoughts that I had as to what the procedure would be" and, "I think a lot of the questions we've been able to

Table 16

GROUP COMPARISON OF SUBJECT INFORMATION SEEKING PATTERNS

	Usual	Video
Nurse	6	2
Radiation Oncologist	0	5
Referring Physician	3	0
Other	0	1

answer have been from the video. We were more involved with it through the video than we would have been just in conversations, say, with the doctor, because pictures show a lot, what do they say...they are worth a thousand words".

Several individuals made special note of the importance of the inclusion of patients in the videotape format: "You know, you see a lot of documentary tape things that are--OK...this is the machine we are going to use and this is how...yes, that is informational too, but it is not as personal and this (videotape) is very personal", "Getting it straight from the horse's mouth so to speak", "When you see somebody who is talking, you know, like a normal person...'yeah, well, then they did this to me', and they explain it like anybody would when they were talking, but not like a book" and, "It is so informational, and it is very candid, too. The people you know, were very honest. It was great".

When asked if videotape viewing impacted on the subject's ability to communicate with the patient, two subjects noted that it did not change their communication because it was always very open. This remained a constant for them during the radiation therapy experience, "We never had any difficulty talking about it at all". Five subjects did report that it made communication easier for them. "We were able to communicate, we knew what we were talking about. She had been through it and I saw it".

The experience of viewing the videotape at home rather than in the hospital offered subjects the additional benefits of watching the videotape with the patient, thereby enhancing communication between each other, sharing the tape with other family members, and having the option of seeing the tape several times. Several people who had chosen to see the videotape at home, highlighted their enthusiasm about the process in the course of the interview. "We watched it together and we knew what she was going through...and so it encouraged our decision by watching the video (to choose a lumpectomy instead of a mastectomy)... (that it was) pretty apt to be OK...that was a big plus." Interviewer: "Do you think that your experience here has contributed to being open about it?" Response: "Oh, definitely, yeah. By both watching the tape and being together at each meeting...that is the biggest thing. Caring persons share what each other is going through."

Another subject reports, "Well we brought it home and we saw it with my son's family and my daughter and her family were unavailable to see at that time so we borrowed it again and showed it to them...And it was still very impressive the second time, as it was the first". The same individual noted that it helped him to talk to his wife more candidly about the experience and it had reduced his apprehension, putting his mind "more at ease".

One individual who chose to take the videotape home found it difficult to watch the program on the first "pass". "It was kind of funny because when we first got it, my wife Judy had watched it and even though I wanted to, I didn't." The nurse sent him home the next day with instructions to "make sure you watch it". He reported that, "After I watched it, I was very happy that I did...feeding the information to you, knowing how other people are affected and just understanding it". In fact, this subject watched the videotape two additional times after the first viewing!

One person felt that she would like to have had the experiences of more patients included in the videotape. "I would have liked more...You know, they showed the guy going for his treatment one day. If there were more of that, like you know, maybe people who had different things, because I know that different people have different kinds of treatment." Another subject suggested that less would have been better. "I'd like the whole story. Maybe using fewer patients and I would like the story from start to finish, how they first got the disease and how they first thought that they were sick, what the symptoms were in the beginning." When one subject was asked about the length of the videotape, she replied, "They (patients and family members) could probably watch something about it for 2 hours and would be picking up (things) still. With any kind of a disease like this, you are always looking for an answer". Interview results indicate that the subjects unanimously felt that the videotape was an effective educational tool which served to address many of their questions.

Other Observations

All individuals who were interviewed were asked to share any other thoughts they had about their experiences in the clinic. Again, the excellence of the staff was noted repeatedly. One subject expressed her concern in interpretation of her responses to the Mental Health Inventory. "When I was filling out the questionnaires, some of the answers I put I felt like I should be writing an essay because I have two kids...One of them had something to do with 'can you remember the last time you got a good nights sleep'...I have two kids so..." Individuals administering the Mental Health Inventory report that this concern was expressed by a number of subjects.

Several people discussed the renewed hope they had found. "After they told me the discouraging news in the beginning, anything now is uphill. We feel and we've heard others that have been here and are on the road to recovery so we feel very confident." "I know when (I hear) the word cancer now, you don't feel numbstruck, you know. You understand that there could be a cure and that you could learn to live with it." "I think that the cancer treatment is more hopeful than I thought it would be. Before I thought when you had cancer, that was the end, but this gave me a feeling that there is hope for the person with cancer and a lot of it can be cured."

Videotape Assessment

All subjects from the Videotape Treatment group (n=14) completed a Videotape Assessment (see Appendix G) in the third week of the patient's treatment. Subjects were first asked to rate the videotape on a scale of 1 to 7 according to 10 descriptors which were presented in paired antonyms (i.e. easy to understand - hard to understand; clear - confusing), 1 being the most favorable rating. The average score for each of the 10 items was 1.6 and ranged between 1.3 and 2.0, 1 being the positive extreme of the continuum (see Table 17, page 146). This reflects that subjects liked the videotape, found it easy to understand, clear, important, worthwhile, useful, informative, calming, and felt that it contained good photography.

No respondents reported that the videotape had too many facts; 93% (n=13) said that it had the right number

Table 17

VIDEOTAPE ASSESSMENT RESULTS SUMMARY

Descriptor	Mean[a]	SD	Range
Likable	1.5	.85	1-3
Understandable	1.3	.61	1-3
Clear	1.3	.61	1-3
Important	1.5	.76	1-3
Worthwhile	1.5	.65	1-3
Photography	1.5	.76	1-3
Useful	1.9	1.0	1-4
Learned a lot	2.0	1.1	1-4
Calming	2.0	.96	1-4
Answered questions	1.6	.93	1-4

The film had:	Frequency	%
too many facts:	0	0
right number of facts:	13	93
too few facts:	1	7

The film made it easier/harder to talk with doctors and nurses:

easier:	11	79
harder:	0	0
no difference:	3	21

[a] 1= most favorable rating; 7= least favorable rating

of facts and 1 person felt that it included too few facts. When questioned whether the videotape program made it easier or harder to talk with doctors and nurses about the illness and treatment of the person the subject was accompanying to therapy, 11 (79%) reported that it had made this easier for them, 3 (21%) noted that it didn't make a difference, and no subjects felt that it made the task harder.

The assessment included four open-ended questions: What did you like best about the videotape program? What would you suggest be done differently? In what ways did the videotape help you? Any additional comments? Subject responses to these questions are summarized in total in Appendix K.

In response to the question regarding what subjects liked best about the videotape, two themes emerged. First, individuals noted that the videotape was effective in imparting information which was of concern to the viewers: "Watching the videotape made it easier to understand what radiation therapy is all about." "It explained a lot of things that I think everyone has questions on radiation." "I understood what procedures my wife was undergoing. And we could talk about it. (What) I liked best was the explanation of the machine and marking."

Secondly, the impact of having patients, "real people" provide the bulk of the information reportedly offered viewers positive role models and served to allay fears and instill optimism and hope about the ensuing treatment, as noted in the subject's following responses to what they liked best about the videotape: "The patients seemed to take their radiation treatments in a calm and relaxed manner". "Rather than being just informational it showed real people who shared their experiences." "All the patients appeared very comfortable with the process and confident with their doctors, nurses and technicians." "The optimism of the patients that were in the film plus the ease that they explained their own stories." "Real reactions from real patients. The patients conveyed positive attitudes which I feel must be reassuring to new patients viewing the film."

When asked what should have been done differently in the videotape, one individual did report that she would have preferred using fewer people with each individual "telling their story from start to finish". Another subject thought that the film could be viewed before the first visit. No other suggestions were offered by viewers.

The viewers responded to the task of identifying the ways in which the videotape helped them in a similar manner to those things that they said they liked best about the program, specifically, the delivery of good, useful information and offering positive role models. They report: "It helped to understand what this therapy is all about." "It is helpful to know that there are people who have had successful experience(s) with radiation therapy." "It showed me that there is hope for people with cancer." "It cleared my mind of what radiation is and took a 'fear' from my mind." A viewer made the following additional comment: "The videotape is most helpful because the information is coming from people who are undergoing or have undergone radiation therapy, so you get the patient perspective."

Subject data on the Videotape Assessment were analyzed for differences in responses relative to the subject's sex, age and educational level in an identical manner to that utilized for the Knowledge Assessment and MHI inventory data. None of these variables were found to have an effect on subject responses.

Individuals assigned to the Videotape Treatment group all reported a very positive assessment of the video program. The content of the videotape appeared to be responsive to their information needs, their need to believe in the possibility of an upcoming positive experience in the radiation therapy clinic, and lastly, the need to maintain hope for a cure.

CHAPTER 5

DISCUSSION

The results of the study will be briefly reviewed as a preface to this chapter. The significance of these outcomes will then be explored. Several study design modifications were necessary in the development of this research. The reasons for these changes will be reviewed, along with study design strengths and weaknesses. Finally, general observations about home videotape viewing, empowerment of video program viewers and retention of information will be offered.

Results

Videotape group subjects demonstrated significantly greater knowledge about radiation therapy following viewing of an educational videotape than did Usual subjects ($p<.0005$, df=27). The videotape was received enthusiastically by viewers, as demonstrated by both their verbal and written feedback. These results suggest that use of an educational videotape could be an effective means to impart needed education to the significant others of cancer patients about to undergo a course of radiation therapy. Replication of this study is needed to confirm these preliminary findings.

The group comparison did not reveal significant differences between the Videotape and Usual groups on the Mental Health Inventory as would have been expected given the link between knowledge and emotional well-being which has been demonstrated in other studies (Cassileth and Hamilton, 1979; Cromwell et al., 1977; Egbert et al., 1964). Several study design limitations may have influenced this outcome.

Limited Sample Size

Due to many logistical problems encountered in the execution of the study (see page 157), the sample size for the MHI analysis was restricted to 28 completed subject data sets (Videotape group = 14; Usual group = 14). This limited subject base hindered the possibility of finding significance in smaller changes on the MHI. It would be valuable to replicate this study with greater subject numbers to see if differences become apparent in mental health status.

High Education Level

The average year of schooling completed by all subjects was 12.7 (Videotape = 13.4; Usual = 12.1). This is a high educational level for a random sample, which gives rise to concerns about the effect of subject self-selection. It may have been that individuals with lower educational levels chose not to enter the study at the time of the initial phone call or during the initial meeting. A large number of subjects did self-select themselves out of the study at these points. The data results may have been compromised in that individuals with lower education levels might have benefited emotionally from this type of program more than individuals with greater school experience. This concern is supported by the educational effect found with this subject population. In the six instances where a significant education effect was found, fewer years of schooling consistently correlated with higher reported anxiety, nervousness, restlessness and worry, and a lower reported level of satisfaction with their personal lives as compared to subjects having continued their education beyond high school.

Effective Education and Support in Place

The staff of the clinic were praised highly by virtually all the subjects interviewed. Such descriptors as "capable", "caring", "helpful", "cheerful", "efficient" and "professional" were used liberally. The staff were reported to have provided not only information, but importantly, also provided support and encouragement to family members. This fact might have lessened any potential group differences in the Mental Health Inventory results between groups, particularly given the fact that this post-test was not taken until the third week of treatment, after subjects had numerous opportunities to interact with the staff.

A more accurate assessment of differences in mental health status due to viewing or not viewing the videotape would have been obtained had post-testing occurred at the same time that the Knowledge Assessment post-test was administered. Unfortunately, due to logistical constraints, this was not possible.

Effectiveness of the videotape should be tested in facilities which have staff who are less able to attend to the needs of patients and their significant others, to better assess its potential as a tool to improve the mental health status of the significant others of cancer patients. For instance, another Worcester hospital which has a fully functioning radiation therapy unit has **no** nursing staff. Employment of the videotape in this setting might well yield different results on the Mental Health Inventory.

Significance of Results

Statistical analysis revealed a substantial knowledge gain for Videotape subjects as compared to the Usual group. This information, coupled with data from the two qualitative measures incorporated into the study, provides valuable insight into the potential use of videotapes in the health care setting.

Contribution to a Limited Research Base

Prior to this study, only Cassileth (1982) had tested the use of videotapes as an educational tool to assist the next-of-kin of cancer patients undergoing various cancer treatments (including radiation therapy) in accessing information. Cassileth employed four different videotapes with her subject base of 106 patients and 134 patients' relatives and family members. The data analysis did not discriminate test performance according to each of the four programs (or treatment modalities) or by patient or next-of-kin status. Even if these data were available, the test consisted of only 5 questions. The Cassileth instrument served primarily as a means to assess short term knowledge gain relative to pre- and post-videotape viewing.

This study marks the first experimental designed study to document the usefulness of employing an educational videotape to meet the needs of the significant others of cancer patients undergoing radiation therapy. In fact, it joins the Cassileth (1982) research to comprise the only two studies to identify and discern means to address the information and support needs of patients' significant others.

Identification of Educational Needs

This study is also the first research effort to identify the information needs of the significant others of cancer patients receiving radiation therapy. It demonstrated that their questions are varied and numerous.

The knowledge test confirmed that individuals beginning radiation therapy carry with them little knowledge and many misconceptions about the treatment process. Only 39% of the pretest questions were answered correctly by subjects. A fairly large percentage of individuals were unsure about the pain associated with the procedure, had overestimated or were not sure about the side effects which would be experienced, and intimated that they perceived the process to be relatively debilitating, as reflected in the large number of respondents who were not sure if individuals could work while going through treatment. Twenty percent of the individuals arriving at the clinic did not know whether or not the patient would become radioactive due to treatment. The correct response rate rose to only 70% for the total group at the time of post-testing.

These results lend credence to the assumption that the information needs of this population are great and speak to the importance of providing alternative means to assure that the questions of patients' significant others are addressed.

Implications for Videotape Production

Perhaps the most interesting and telling data about the impact of the videotape were contained in interview discussions and on the Videotape Assessment. The videotape was clearly enthusiastically received by all who viewed it. The basic information presented addressed the majority of the viewers' questions. Beyond this fact, additional important information regarding not only the content but also the format of the videotape was gleaned.

Very little research exists which clearly identifies the critical format issues to be addressed by producers of medical videotapes. Most medical education audiovisual presentations appear to be designed primarily from the practical experiences of the medical professionals involved in the scripting process and based on research which generally identifies areas of information or misinformation about the issue at hand. Although great detail about the nature of the audiovisual format was generally not offered in the other studies, it appeared that interventions most often employed medical professionals to present to patients the information they needed.

As previously noted, the author of this research was the producer of the intervention videotape. One format consideration which was felt to be central to effectively meeting the needs of viewers, was the use of patients as the primary conveyors of information. "Informational interventions that describe the experience from the experiencing person's vantage point have been found to consistently facilitate coping with threatening events in the laboratory (Johnson, 1973;

Johnson & Rice, 1974) and in the health care settings (Johnson & Leventhal, 1974; Johnson, Morrissey & Leventhal, 1973; Johnson, Kirchhoff & Endress, 1975)" (Johnson et al.,1978, p. 7). For this reason, a group discussion with patients, facilitated by the radiation therapy nurse, was the basis for the study's videotape.

It was believed that this "technique" would impact on the viewer in several important ways: 1. Viewers would understand that their questions were both legitimate and shared by others. 2. Viewers would gain reassurance by visually having witnessed, from a patient's perspective, what a treatment is all about 3. Viewers would gain hope by seeing individuals who had successfully completed radiation therapy 4. Viewers would recognize the clinic staff's respect for and understanding of the patient's issues and therefore would feel empowered to more readily approach the staff in seeking answers to their questions.

Although evaluation of these assumptions were not the focus of this research, various components of the data do support the effectiveness of this format choice. In both the interviews and written responses of the Videotape group, subjects voiced that inclusion of the patient perspective offered unique insight into the day-to-day treatment process. In the words of one subject, it was worth "a thousand words". Viewers reported that the patients served as positive role models, helping to instill hope about the impending treatment process and treatment outcomes. Those who saw the videotape noted more readily available access to the radiation oncologist than did those in the Usual group, suggesting a sense of empowerment in satisfying information needs.

Results indicate that structuring the production of an educational videotape so that patients play a primary role in the delivery of information has a positive impact on viewers. These format issues warrant further research to confirm (or deny) the author's four assumptions about patient inclusion in videotape production. Confirmation of the effectiveness of this approach could have a far-reaching impact in the field of patient and family education, significantly improving on the traditional "talking-head" approach to the delivery of information.

Study Design Modifications

A number of study design modifications were made in the original research proposal to assure the viability of this research undertaking. These modifications will first be summarized. The causal factors will then be explored in depth.

Study design changes

1. Four intervention groups were initially proposed. In addition on the Usual and Videotape Treatment groups, subjects were also to be randomized to either a "Nursing" intervention in which the significant other received a counseling session with the nurse, or to a combined "Nursing and Videotape" intervention group. The latter two groups were dropped from the study design.

2. The significant others of "palliative patients" were to be screened from study inclusion. Although this was done on an informal basis by the nursing staff, this exclusion requirement was rescinded.

3. Initially, subject viewing of the videotape was to be restricted to the hospital setting. Early in the study, the Videotape Treatment subjects were given the option of either viewing the videotape in the hospital at the time of the simulation visit or taking the videotape home for viewing. Thirteen of the fifteen Videotape subjects chose to take the tape home.

The author will briefly describe the key factors which caused a data collection process, which was anticipated to be completed within a six month time period, to be stretched to over 27 months before its completion. These factors, singly or in combination, were the impetus for the study design changes noted above. It is important that future researchers working in this area take into consideration these methodological issues.

Research Assistant Status and Qualifications

A lay research assistant was first hired to coordinate the study. The task included enrolling subjects, administering all written questionnaires, assuring that the intervention was administered in a timely and correct manner and conducting the final interview. The woman hired for this position had worked with oncology patients and, as a staff member of the Oncology Division at the University of Massachusetts Medical Center, had developed a program focused on the needs of individuals going through the grieving process from the loss of a loved one. Through this experience, she gained valuable insight both into patient and family issues and into the protocols and politics of hospital-based provision of care for patients. These were important attributes for someone who was to be interfacing with the radiation therapy clinic staff as an "outsider", and as a person who did not have a clinical degree. In fact, the Research Assistant had worked with the radiation therapy clinic nurse who served as the primary contact for the study. At the time she assumed the Research Assistant position, she was no longer an employee of the Center.

The Research Assistant's work was greatly dependent on her ability to effectively interface with the administrative, nursing and medical staff on an on-going basis to ascertain information on potential subjects, to clear schedule time, to find the physical space to enroll subjects, and to complete the follow-up testing sessions. This proved a difficult and frustrating task for an individual outside the "system".

It appeared that the frustration was not due to the staff purposely impeding the research effort. More often, it seemed that the day-to-day magnitude of the demands on the staff did not allow them to focus on the study. It was not a priority and therefore was not attended to.

As an "outsider", it was difficult to be assertive with the physician staff and with patients about meeting the study protocols. Insight into the internal politics of the unit also left this individual at a disadvantage. The Research Assistant resigned after four months of a concerted effort to attend to the study, which resulted in the enrollment of only four new subjects.

The Nursing Staff as Research Assistants

Several months after the resignation of the Research Assistant, the nurse who had been the primary promoter of the study within the radiation therapy unit offered to orchestrate the data collection process with the help of the other two clinic nurses. As "insiders", the nurses had a working knowledge of the logistics and politics of the system, credibility as trained clinicians with both the medical staff and patients, were able to respond to potential patient referrals quickly, and were in a position to be more assertive with staff and subjects to assure the study's success. Even with these advantages, the study proceeded at what can best be termed a "snail's pace". What factors contributed to the continuing struggle for subject enrollment?

The nursing staff in the radiation therapy unit have little or no control over the nature and volume of demands imposed on them during the course of a day, and very few days are slow. Approximately sixty patients receive daily treatment. The scheduling of simulations and follow-up visits further confound the flow of a day. The nursing staff must respond to the needs of these patients, along with the demands of the physician staff, on an on-going basis. Phone calls are frequent and disruptive. Three nurses share the same office, adding to the confusion. Vacation schedules, pursuit of academic degrees and continuing education credits, and other nursing administrative responsibilites also drained the energies of the nursing staff.

The unit's physicians were equally focused on maintaining control over the patient flow. Allowing the time necessary for subject enrollment into the study sometimes did not fit into the physicians' schedules; nor did the screening of patient charts to assess whether or not the patient was to be considered "palliative" (initially specified as necessary to assess the individual's eligibility for study inclusion). Basic nursing care demands to support the patients often superseded follow-through with study protocols. For example, every Monday all patients are scheduled to meet with the radiation oncologist and nurse responsible for their care. The nursing demands for assessing and monitoring their primary patients as well as setting-up patients in the rooms and offering physician support for the process made it nearly impossible to attend to the study on this day.

In recognition of the growing demands, the staff has increased steadily over the past two years, going from one full-time member to three. This has not served to noticeably lessen the often frenzied pace at which these individuals work. This may be due to the fact that new technologies are being added to the clinic which demand nursing time, as well as an increase in the patient census. For example, more work has been done in the area of the treatment of children.

Attending to the child and to the family members required a focused, intensive nursing effort. Recently, hyperthermia has been added to the treatment options at the clinic. This technique requires that probes be inserted into the patient's tumor so that the area can be heated to a higher than normal temperature. The theory is that this makes the tumor more susceptible to the radiation treatment. The entire process takes an average of three hours and a nurse must monitor the patient at all times throughout the procedure. And so, although the staffing level has increased, each nurse continues to confront a continuously demanding and somewhat unpredictable daily schedule. The focus of their efforts rests with attending to the patient's needs. They reported that this reality often made it difficult to assist in the implementation of the study.

It was for this reason that the "Nursing Intervention" and the combined "Nursing and Videotape Intervention" were removed from the study design. It became clear that it was all the nursing staff could do to meet the basic nursing demands of their job. The purpose of the study was to research and document reasonable alternative means to meet the needs of the patient's loved ones. Therefore, it was deemed impractical to test two interventions that would not realistically fit into the scope of the clinic services.

Eighteen months into the data collection phase, only five subjects had completed the study protocol. Recognizing this fact, the nursing staff renewed their commitment to complete the study. They reported that it became their "crusade". The nurses became more assertive with patients and family members during the enrollment process, and were more insistent with the medical staff that they must support this effort. The pace improved to a crawl, which in itself was a dramatic improvement.

Transportation

Soon after the study began, the University of Massachusetts Medical Center instituted a van service which was available to provide transportation for radiation therapy patients from distant sites. The research requirements specify that the significant other of the patient must accompany the individual to the clinic a minimum of three times during the course of treatment. Prior to the van service, this often naturally occurred because the family member or friend was the patient's source of getting to and from the clinic.

Family members were allowed to ride the van with the patient but in most instances they did not consistently accompany the individual to treatment. The transportation demands of a six week course of treatment had often posed a severe hardship to the family members and friends of patients. The van service was a tremendous asset to the services provided by the radiation therapy unit but took its toll on the subjects available for enrollment in the study.

As previously noted, families and friends often share the responsibility of providing transportation for the patient to and from treatment. For this reason, a number of patients who were called the day before treatment could not identify one person in particular as a potential subject for the study. Also, in several instances, last minute changes in the subject's schedule resulted in another person transporting the patient at one of the study intervention points. This breach of the study protocol necessitated that these individuals be dropped from the study.

Fluctuations in Patient Load

The frequency of referrals to the radiation therapy clinic of individuals who would potentially fit the study inclusion criteria (i.e. not palliative and first time treatment) tended to have its own cycle of highs and lows. Some weeks, four or five eligible patients would be scheduled; other weeks, no eligible patients would be noted in the appointment book. Even on the busiest of weeks, no more than two subjects entered the study. This variation in referral patterns set-up a "Catch-22"; the busier the week, the more the potential available subjects but the greater the other demands which distracted staff from focusing on the study.

It was also not unusual for referrals to be arranged directly with the physician and appear in the schedule book only at the last minute (if at all). This process did not allow the nursing staff to contact the patient in advance of their first visit so that they could be screened for enrollment.

Another variation of the scheduling problems which impacted on the design changes was when the physician would carry out the initial meeting with the patient and significant other and then unexpectedly simulate the patient immediately thereafter. (Normally, several days elapsed before simulation occurred). In this instance, it was not always possible for the research assistant or nurse to arrange for the appropriate intervention for the subject.

Study Enrollment During a Period of High Anxiety

It is clear that both the patients and their loved ones experience fear and apprehension when beginning the process of radiation therapy and know little about what is entailed (Tringali, 1986; Beck and Boland, 1977; Holland et al., 1979; King, 1985; Strohl, 1988). It is not unusual for people to question whether the patient will be radioactive when they return from the clinic. Frequently individuals will confuse chemotherapy treatment with radiation therapy treatment, the former often having more debilitating side effects.

Most of the study subjects who were interviewed indicated that they had little or no knowledge of what radiation therapy was prior to accompanying the patient to treatment. This fact was confirmed by the subjects' performance on the Knowledge Assessment pretest. One subject vividly recounts his friends telling him horror stories of the difficulties they had while going through treatment such as severe burning, stomach aches and nausea, intimating that his wife would experience the same problems. It is safe to assume that this individual was not the only subject living with troubling misinformation about the treatment process prior to the first clinic visit.

The study protocol required that the patient be called several days before their first visit to the clinic to do a preliminary assessment of possible inclusion of the patient's significant other in the study and to ask them to come to the clinic one-half hour before the scheduled appointment to learn more about the project. At this point in time, the patient had not met the individual on the other end of the telephone line. The research assistant and nurses reported frequent refusals on this first phone encounter. The reason most often cited was the patient's and/or significant other's inability to deal with or commit to one more thing. Often transportation issues had not yet been addressed or resolved. Heightened anxiety and fear were often clearly evident in the patient's voice.

During the enrollment visit, which immediately preceded the first encounter with the physician, this anxiousness often became almost tangible. Many additional subjects decided not to enroll in the study at this point.

Summary

The logistical constraints encountered in conducting this study necessitated several methodological changes in the research design. Finding a research assistant(s) who had the status and qualifications to work effectively within the system but who did not experience the bind where the "window of opportunity" of subject enrollment coincides with the "window of inordinate patient demands" is critical to expediting this type of research. This individual clearly must be able to influence departmental priorities by gaining the acceptance and support of the medical staff.

Several other factors limited the pool of individuals who were eligible and available to be screened for inclusion in the study. Changes in transportation plans by the institution and within families greatly diminished the number of patients who were accompanied consistently by their significant other. This fact, coupled with fluctuating patient referrals, an enrollment process occurring during a time of relative crisis for the patient and his or her family, and research staffing constraints resulted in great difficulty in obtaining a satisfactory number of subjects within a reasonable time frame. These issues are, to a large extent, unavoidable realities when conducting research with this population, beyond the control of the institution, the patient or the researcher.

Study Design: Strengths and Weaknesses

The methodology of this study improved on those methods employed in the study designs of comparable research in this area in two key ways:

Testing of Longer-Term Knowledge Retention

Many of the studies which have sought to measure the impact of a medically oriented audiovisual intervention on viewers' knowledge have done so by an immediate pre- and post-testing process (Alkhateeb et al., 1975; Bakker, 1987; Cassileth, 1982; Colton et al., 1986; Moldofsky, 1979; Williams and Manske, 1987). This study design allowed for the possibility that test results were unduly influenced by the "clueing" which occurs by taking an identical pre- and post-test within a short time interval. The subject knows what the questions were he/she did not know on the pretest, views the program intently seeking answers to these questions, and completes an immediate post-test where short-term retention of the answers results in a high score and a significant difference from the pretest performance. This difference is a legitimate one, but interpretation of the results must be limited only to the short-term impact of the intervention.

The Cassileth (1982) study was the only educational research effort which enrolled the family members and relatives of patients and therefore served as a model for this research. However, Cassileth (1982) noted that, "the process of pretesting, program viewing, and post-testing required approximately 45 minutes" (p.56). This research is therefore subject to constraints in interpretation as noted above.

It was felt that extending the time interval between viewing of the videotape and completion of the knowledge post-test was an important improvement over the study design employed by Cassileth (1982) and others. The lengthened time interval following viewing of the videotape lessened the possibility that the resultant effect was due in large part to only short-term memory retention of the material.

Ironically, the decision to lengthen the time between pre- and post-testing on the MHI may have diminished the study effect by introducing numerous confounders which had the potential to essentially "wash-out" mental health differences.

Utilization of a Comprehensive Mental Health Inventory

Employment of the Rand Mental Health Inventory, a 38 item measure of psychological distress and well-being, allowed for analysis of changes in the subject's emotional status according to five key markers: anxiety, depression, loss of behavioral/emotional control, emotional ties and positive affect. These markers have been reviewed in depth in the preceding literature review as aspects of the emotional status of the significant others of patients which may be impacted by the cancer diagnosis and subsequent treatment process.

Many studies have not included any assessment of the effects of audiovisual interventions beyond knowledge gain (Black and Mitchell, 1977; Darr et al., 1984; Israel and Mood, 1982). They have generally suggested that knowledge gain would naturally result in a better mental health status for the viewer. A few studies have identified and tracked specific behavioral markers in patients (Lawson et al., 1976; Johnson, 1988; Mulrow et al., 1987; Moldofsky et al., 1979; Williams and Manske, 1987), and the modeling studies focused primarily on anxiety reduction (Melamed and Siegel, 1975; Padilla et al, 1981; Shipley et al., 1978; Vernon, 1973) . All these research efforts have used patients as their subject base.

The Cassileth (1982) study did include the patients' relatives and friends in addition to the patients themselves when they tested both knowledge and anxiety changes in the study population. The subjects' anxiety levels were documented by use of a standard anxiety test called the State-Trait Anxiety Inventory (Spielberger, Gorsuch and Lushene, 1970). The results of this study revealed that relatives demonstrated significantly higher anxiety levels than did patients on the pretest ($p<.004$) and on the posttest ($p<.05$).

This research utilized a more comprehensive mental health assessment to expand on this base of knowledge and further discern the specific changes in the subjects' emotional status due to the intervention. It served as a unique opportunity to contribute to the current limited research data about the general mental health status and needs of this population.

The MHI is a comprehensive, well-validated instrument, however, it may not be the most appropriate means to measure the mental health impact of health education interventions. A testing tool that that is as broad in scope as the MHI, yet is more sensitive to the discrete behavioral markers comprising the assessment may yield clearer results.

Several design limitations warrant noting so that they may be considered in the development of future research efforts:

Possible Biases

The physician who counseled the patients and significant others during their first visit to the clinic could not be blinded to their status as study subjects. This was due to the fact that of necessity, he was active in the recruitment of individuals into the study. Also, he often had to wait until the enrollment meeting was finished to conduct his meeting, thereby revealing their study status. This may have in some way influenced the nature and depth of the session with the physician, possibly contributing to better MHI subscale scores for subjects in the Usual group. This would serve to diminish any mental health effects due to videotape viewing. In addition to the potential physician bias, several other possible biases were inherent in the study methodology.

The videotape being tested was produced at the University of Massachusetts Medical Center with the staff members of the radiation therapy clinic actively participating in the program. It may be that the responses of subjects in the Videotape Intervention group were biased by their subsequent personal relationship with the staff who had been part of the videotape. It is important that this study be replicated in another setting, thereby negating this potential bias.

The researcher initially sought an "outside" research assistant to make it possible to keep the nursing staff blind to the subjects' study group assignment. Theoretically, this would have assured that the nursing staff did not in any way treat the subjects differently relative to the study group they were in. In fact, even this measure would not have guaranteed group assignment anonymity, as clues to group assignment would have been easily observed or overheard in the limited physical space of the clinic.

As previously discussed, the nursing staff ultimately orchestrated the study data collection process. For this reason, the potential bias of the nursing staff may have influenced subject responses on the instruments they asked subjects to complete and might have subconsciously changed the way they interfaced with these individuals. Given the unanimous positive review by all subjects regarding the staff, it does not appear that favoritism of one study group over another was blatant between the Usual and Videotape Treatment individuals, but may have existed none the less.

Subject Self-Selection

Many newly referred radiation therapy patients were not entered into the study in accordance with the exclusion criteria initially set forth. The nursing staff estimated that out of the approximate 10 new patients referred to the clinic on a weekly basis, five were immediately screened out as ineligible (i.e. second treatment course, palliative treatment). Of the five remaining individuals, it was often difficult to reach a number of these persons at home to assess eligibility. Of those who were contacted, approximately three out of every four were either excluded in keeping with the study inclusion criteria, or preferred not to be involved. It was the research assistants' beliefs that refusal to be part of the study was greatly attributable to the individual's existing stress level. The treatment program was intimidating but largely unavoidable; the study was intimidating and totally avoidable. It may be that a non-representative selective sample was obtained because of this self-exclusion process, as witnessed by the high educational level of the study group as a whole. No data were collected from this group to provide further insight into their similarities and differences from the study subjects.

General Observations

Home Videotape Viewing

Interviews and written responses by the individuals in the Videotape Treatment group who saw the tape at home, strongly indicated that great benefits can be derived from viewing of the film in this setting. The hospital setting heightens the anxieties of patients and family members. In this state of mind, it can be difficult to retain the information presented by the medical staff. Often questions are not asked or even remembered until the trip home. The impact of a patient’s significant other viewing an educational videotape in the hospital may be compromised by this anxiety level.

When the patient viewed the video with the significant other present, it offered a common starting point for them both. In a number of instances it made it easier to discuss the impending treatment process and lessened fears and misconceptions, replacing these sentiments with knowledge and hope. Several subjects noted that home viewing allowed an opportunity for other family members to have their questions and concerns addressed by means of the videotape, further opening up lines of communication.

Usually a limited number of family members accompany the patient to the hospital. Those at home are very removed from the experience and are at great risk of not having their informational needs met, for it is safe to assume that they have no fewer concerns and questions than the individuals accompanying the patient to treatment. If the educational intervention excludes the patient and concerned others, they do not benefit from the shared experience of learning together and the ease of communication which can be prompted by this.

Very importantly, it also deprives them of role models, other patients who have successfully completed treatment. Instilling hope through role models was noted as a very helpful part of the film. The videotape may be the only way to offer role models to family members, relatives and friends who otherwise do not have direct experience with radiation therapy treatment. It is an alternative means to lessen the isolation that occurs for the patient and for individual family members when life becomes consumed by the cancer diagnosis and treatment protocols.

As reported in the results section, one subject took the videotape home but could not bring himself to view it. "It's kind of funny. As much as I have plenty of time to do a lot of different things, not like most people...I just really didn't think about it at that point right there. After I watched it, I was very happy that I did." Shipley (1978) might have labeled this individual a "repressor", someone who is overtly non-anxious and deals with the stressful situation by not thinking about it. With gentle prompting, this individual did view the videotape, not once, but three times. He reported that in fact it did help to "ease his mind", answering many of his questions and concerns. This occurrence suggests that home viewing of videotapes may be a relative low-threat means to reach "repressors" with a hopeful and informative message about some aspect of the care of their loved one; knowledge and reassurance which they may otherwise not benefit from, due to their general reluctance to pursue answers to their questions.

Empowerment

The literature supports the fact that access to information by the patient's family members is often felt to be a problem (Northouse, 1986; Wright and Dyck, 1984). Therefore, one desired outcome of videotape viewing was to empower the subjects to feel comfortable in aggressively seeking answers to their questions. This anticipated outcome was in part based on the findings of the Cassileth (1984) study where the impact of videotape viewing on cancer patients and their family members was assessed. Sixty-nine percent of viewers of

Cassileth's (1985) educational videotapes did report that watching the video made it easier to talk with doctors and nurses about their illness and treatment (p.58). When asked to describe why this was so, the subjects responded: "The film provided enough background information to ask pertinent questions." "It gave me a base of information to work from." "You have to have some information in order to ask an intelligent question."

Similarly, 79% of the subjects in this study's Videotape Treatment group did report that viewing the videotape made it easier to talk with doctors and nurses about their questions. It was also interesting to note in the clinic interviews that when asked which staff member the subject would go to, to seek information about the patient's treatment, 6 individuals in the usual group identified a nursing staff member and 3 noted the referring specialist. No subjects from the Usual group suggested that the first person they would seek information from was the treating physician. In comparison, five of the Videotape Treatment group members said that they would go directly to the radiation oncologist, two noted that they would seek the information from the nursing staff, and one would go to a friend who had a medical background.

This self-reported effect of the videotape, coupled with subjects' reported perceived access to the radiation oncologist by five individuals in the Videotape Treatment group in comparison to none in the Usual Treatment group, may indicate that the viewing of the videotape did in fact empower these individuals to feel less intimidated in satisfying their informational needs by going directly to the physician for answers to their questions. The empowerment of videotape viewers to more readily seek answers to their questions warrants further study. Specifically, a direct comparison between control and experimental groups relative to information seeking behavior should be developed. Predictably, increased knowledge and a sense of control over the situation will lessen the anxiety of both family members and friends.

Retention of Information

"'Just because you've said something doesn't mean it's been learned' is an admonition from Carl Rogers that should form the underpinning of any patient education activity," writes Swezey and Swezey (1976, p.417). This clearly also serves as an underpinning for any educational activities for the significant others of patients. Following an in-depth discussion about radiation therapy with the radiation oncologist and viewing of the video, the Videotape group on average only correctly answered 77% of the knowledge questions. The Usual group correctly responded to only 59% of the knowledge post-test questions.

Swezey and Swezey (1976) note that," Patient (and family) motivation usually is heightened by the anxiety that accompanies his concern about health, but an excessively high degree of anxiety or depression may preclude any learning or adaptation" (p.418). Acknowledging the anxiety which accompanies the cancer diagnosis and treatment process, it is essential that multiple approaches to the delivery of information, namely verbal, written and audiovisual, be utilized to assure understanding of the issues at hand. This "potpourri" strategy will assure that whatever the favored learning style and whatever the learning readiness of individuals, information will be offered in a medium that suites their needs. "Flexibility in educational methodology, making available a variety of visual and auditory techniques, will maximize the effectiveness of an educational curriculum" (Swazey and Swazey, 1976, p.420). It is clear from the results of this study that only through repetition and reinforcement of information via several educational mediums, will key issues in the treatment process be understood.

Discussion Summary

The significant findings of the study were first reviewed. Comparison of knowledge post-test performance of the two study groups revealed that Videotape subjects knew significantly more about radiation therapy than did the Usual group. Videotape subjects consistently expressed satisfaction with the content and format of the video in both the written assessment and in interviews. The majority of individuals who saw the film reported that it facilitated communication with doctors and nurses. They also noted that the videotape provided helpful, readily understood information which served to lessen their fears and offered optimism about the future.

Insight was offered into three possible key reasons why the MHI study instrument revealed no significant intervention effects. These reasons were as follows: 1. the limited sample size 2. a relatively high educational level of subjects and 3. the existence of very effective education and support resources within the clinic.

The author then highlighted several ways in which this study has contributed in a meaningful way to the limited research in this area. Specifically, it is the only attempt in the published literature to document an effective educational strategy for this population. or to profile the informational needs of the significant others of cancer patients undergoing radiation therapy. Additionally, the research is one of only a few study efforts to shed light on videotape formatting issues regarding the impact of patient inclusion in information delivery.

Modifications in the study design were reviewed and reasons for these changes were detailed. Specific methodological problems which hindered implementation of the study were conflicting demands on the research staff, transportation alternatives, fluctuations in the patient load, and study enrollment during a time of high anxiety for the patient and family.

Both the strengths and weaknesses of the research format were presented. Specifically, this study delayed post-testing to assure that longer-term retention of information was assessed. Also, a comprehensive mental health inventory was employed rather than a limited, discrete measure for only one outcome indicator (i.e. anxiety). Importantly, concerns regarding the sensitivity of the MHI with this population were reviewed. The possible biases of staff knowledge regarding study group assignment, personal relationships with staff who were in the videotape and subject self-selection were described.

Finally, general observations about the usefulness of home viewing, empowerment of family members to be aggressive in seeking answers to their questions, and the importance of acknowledging difficulties in information retention were offered.

Chapter 6

SUMMARY, IMPLICATIONS AND CONCLUSIONS

Summary

The purpose of this study was to evaluate the impact of two educational interventions on knowledge level regarding radiation therapy, and on the emotional dispositions of the significant others who accompanied cancer patients to outpatient radiation therapy. Two groups of significant others were created. The Usual Treatment Group received the education and counseling services generally offered to all patients and family members receiving care at the radiation therapy clinic at the University of Massachusetts Medical Center. In addition to these services, the Videotape Treatment Group saw a video program designed to address many of their information and support needs.

Comparison of the knowledge post-test performances of these two groups revealed that Videotape subjects knew significantly more about radiation therapy than did the Usual subjects ($p<.0005$). The groups did not differ any in their mental health status at either testing session.

Videotape subjects consistently expressed satisfaction with the content and format of the videotape in both a written assessment and in interviews. The majority of individuals who saw the video reported that viewing the film made it easier to talk with the doctors and nurses. They also reported that the videotape provided helpful, readily understood information which served to lessen their fears.

These same subjects frequently noted that the incorporation of patients into the video program enabled them to approach the clinic experience with a hope they had not previously thought possible. Watching and listening to patients who had successfully completed treatment allowed them to believe that at a future time, their loved one could similarly reflect on a successful experience.

Implications for Future Research

This study represents the first steps into an area that beckons further investigation. This is a time when medical technology is advancing at an exponential rate, introducing newly diagnosed patients and family members into a complex and foreign world of medicine. Staffing shortages resulting from cost containment measures compound the frustrations of patients and their loved ones in attempting to gain insight into clinical problems and procedures. The usefulness of videotapes as an educational tool in the realm of medicine needs to be studied, to lend credence to an alternative means to address this serious deficit in the health care system.

A number of valuable insights were gained in the process of this research effort. The following are six suggestions to guide future study in this area.

Obtain a Larger Sample Size

The logistical difficulties of securing a larger subject base must be addressed to assure that the smaller study effects can be statistically documented. Significant others will always be a difficult population to reach. Even studies of the use of audiovisuals with patients, a far easier subject base to access, have noted difficulty in developing a tightly controlled experimental design. Rainey (1985) notes, "Due to several logistic and clinical factors, the medical staff deemed it undesirable to assign successive new patients randomly to intervention conditions" (p.1057). A non-random sampling was the compromise position assumed to assure that the study was viable. Immediate post-testing following videotape viewing is another example of a design choice which greatly eases the logistical difficulties of implementing a study and assures obtaining a reasonable subject base, but also limits interpretation of the findings.

It may be that some of these design compromises are unavoidable in these beginning efforts to develop a better understanding of the education and support needs of the patient's loved ones. Great thought and attention should be given to the information lost by less rigid study designs versus the information gained. It is essential that researchers not be dissuaded from work in this realm. Surmounting these logistical hurdles may yield rich results, contributing to our meager understanding of this population.

Development of the Home-Viewing Concept

Viewing of the videotape in the home setting offered important benefits for subjects. Future research should be developed to test for the effect of viewing a pertinent medically oriented educational videotape on the family unit. A number of individuals interviewed alluded to the helpfulness of showing the videotape to other family members, but the study design did not formally assess this effect. Important questions left unanswered were as follows: How did viewing the videotape impact on other family members' knowledge and mental health status? Did viewing enhance their ability to talk to the patient about the issues at hand? Did role models offer hope that their loved one will successfully complete treatment? Was the sense of isolation often felt by family members lessened by a more complete understanding of the treatment procedures and the provision of a common language to discuss their questions and concerns? Did it effect their overall information seeking patterns?

Videotape Viewing Prior to the Initial Visit

The radiation therapy videotape should be viewed prior to the patient's first visit to the radiation therapy clinic. This would serve to minimize the window of time that patients and family members live with misinformation about treatment and the subsequent heightened anxiety which so often accompanies this lack of knowledge. If this could be orchestrated, one would assume that individuals would enter the treatment process with a far greater degree of comfort and enhanced sense of control, having already had many of their questions and fears allayed. Design of a study to test these assumption would require enlisting the help of the primary care physicians and specialists who refer the patient for radiation therapy. Provision of the video for home viewing at the time the patient was told of the referral for radiation therapy promises to be perhaps the most innovative and effective use of the videotape. Only formal study in this area will confirm this assumption.

Inclusion of Patients in Videotape Format

Is incorporation of patients and/or family members into the videotape format as powerful a tool as has been suggested by the author? The comments of subjects would infer that this is so, but in-depth research focused on format issues must occur to verify this effect. If, as the author suggests, videotapes are to play an integral role in patient and family education, it is imperative that guidelines and standards about their content and format be formulated to assure the quality of this effort.

Inclusion of Lower Socioeconomic Status Subjects

It is known that, "particularly patients from a low socioeconomic status rely heavily on oral or visual media" (Swazey and Swazey, 1976, p.420). This was demonstrated in the Cassileth (1982) study where a strong educational effect was found. The influence of the subjects' educational experience in this study reaffirms the importance of this consideration. Development of a research design must assure that the enrollment procedure does not allow for selecting out lower socioeconomic status individuals, thereby skewing the sample and possibly limiting the study effect.

Effect of Family Videotape Viewing on the Patient

"Relatives do provide a psychosocial environment to which the patient reacts and, conversely, that patients similarly influence the level of distress or adaptability exhibited by their relatives. Supportive intervention for the patient and relative, when either or both display distress, should have a mutually enhancing effect" (Cassileth, 1965, p.76). It would be valuable to study the effect on the patient of involvement of the family in videotape viewing. A yet more compelling argument for development of family-oriented videotape educational interventions would be rendered if it was proven that this effort significantly facilitated the patient's ability to cope.

Implications for the Medical Profession

The use of videotapes by the medical profession as a component of patient and family teaching may provide a means to enhance the coping skills of the patient's entire family unit, thereby ultimately improving patient outcomes. It may also lessen the growing frustrations of doctors and nurses created by increasing patient care responsibilites in the face of diminishing staff support. At a time when the sophistication of technology prompts more challenging and complex questions from patients and family members, nurses and physicians are finding less and less time available to adequately respond to these needs.

Utilization of videotapes to provide basic information about the patient's disease diagnosis or upcoming treatment or procedure may serve to optimize personalized teaching sessions with medical and nursing staff. Videotape viewing could minimize the sometimes tedious review of basic information. It would allow for key points to be more quickly summarized in a teaching session and focused questions solicited relative to this basic information. This time-savings would allow for increased opportunities to address the unique concerns and questions of the patient and family members. In this way, the use of videotapes may improve the overall quality of medical care received. In the process, it has the potential to enhance the professional satisfaction of nursing and medical staff.

Conclusions

The art of medicine demands that one recognize the patient as not only an illness to diagnose and treat, but also as a spirit, full of hopes and fears. It requires that the patient be cared for as a whole person, rather than a disease entity.

An essential part of a patient's being is his or her role as part of a family unit. Family members are one step removed from the patient's ongoing tests and treatments and may not comprehend as clearly the rationale, the anticipated gains, the side effects or the setbacks that accompany each turn in the road. They too, wage a constant war between hope and fear; a war which can ultimately effect the patients' ability to cope with illness.

There is a growing emphasis in the medical profession on honing technological skills instead of interpersonal ones. "Modern physicians, more than men and women in other professions dealing with people, must now use technology intimately, continually, and expertly. The physician has become a prototype of technological man" (Reiser, preface p.X). Thus, many physicians find themselves less well equipt to address the emotional needs of the patient and family at a time when these needs are increasing in direct proportion to technological advances. This situation is exacerbated by trends in the health care reimbursement sector which minimize patient counseling time.

"Time is the one thing that patients need most from their doctors - time to be heard, time to have things explained, time to be reassured" (Cousins, 1979, p.137). Yet, the insurance industry will pay thousands of dollars for a surgical procedure, but will not reimburse the primary care physician to counsel and support patients and family members in their travels in and out of the medical domain. Insurance companies closely monitor the length of hospital stays, requiring that patients be admitted at the last possible moment and be discharged at the earliest possible opportunity. H.M.O.s limit patient interactions with physicians by imposing productivity quotas.

Nurses have always played a central role in addressing patient and family concerns. At a time when nurses could be instrumental in responding to the growing void in patient and family education, they are facing skeleton staffing situations. This has resulted in less nursing time to provide education and support, and serves to further fragment care delivery.

This is a changing world of medicine. New means to assure that quality medical care is maintained are needed. Videotapes may be one form of today's technology which can help to enhance the psychosocial aspects of medical care delivery, providing information and hope for patients and their loved ones. This study lends further support to the assertion that videos are a valuable resource to supplement the heart-felt personal support and education by nurses and physicians which lie at the heart of medical care.

"The large treatment machine is frightening and complex. Left alone to stare into the source of this invisible and powerful force, patients relate that this experience exemplifies the loneliness and isolation of the entire cancer experience" (Strohl, 1988, p.430). Radiation therapy personifies the technological age of medicine. We know that information and reassurance can help patients cope with "simulations", "linear accelerators" and much more that is new and foreign in their lives (Israel and Mood, 1982; Johnson et al., 1988; Rainey, 1985). The findings of this study and others suggest that an educational videotape is also an effective means to provide information and offer reassurance to the patients' significant others: "It explained a lot of things that I think everyone has questions on radiation." "It took a fear from my mind." "It showed me that there is hope for people with cancer."

The practice of medicine balances science and art. The breathtaking advances in science and technology, together with financial pressures, now threaten to tip this balance. The development and incorporation of audiovisual programs into primary and specialty care appears to be one way to help restore a more evenly weighted approach to patient care.

Rainey (1985) notes that for the patient population, "one need not search for esoteric or complex psychologic interventions when basic information needs have not yet been met" (p.1061). His words echo the cry of family members and friends, who have rights to information about the their loved one's treatment, but who remain largely ignored by a medical system that relies increasingly on outpatient care, thus shifting responsibility from hospital to home. Medicine must rise to this challenge and find new ways to support patients and their loved ones. The creative use of videotapes allows art and science to share common ground in answering this call.

Appendix A

Telephone Procedure

The introductory phone call initiated by the research assistant to assess potential subject involvement.

Discussion with patient:

1. Hello. My name is ( ) and I am working with Dr. Fitzgerald and the radiation therapy clinic on a study to help individuals who are close to a person undergoing radiation therapy to better understand the procedure. I understand that your initial visit with Dr. Fitzgerald is scheduled for _______. Will anyone who is close to you accompany you to this visit? (If yes, go to #2. If no, go to #7).

2. What relation is _______________ to you?

3. Does this person currently live with you? (If yes, go to #4. If no, go to #8).

4. Would it be possible to speak to him/her at this time? (If yes, go to #5. If no, go to #8).

Discussion with significant other:

5. Hello. My name is ( ) and I am working with Dr. Fitzgerald and the radiation therapy clinic on a study to help individuals who are close to the person undergoing radiation therapy to better understand the procedure. I am calling to see if you would be willing to come to the clinic one-half hour before ______________'s (patient) first visit with Dr. Fitzgerald to talk more with me about the study. ________________(the patient) is welcome to be with us during the meeting. (If yes, go to #6. If no, go to #9).

6. I will meet you at the clinic at __:__ on _____(month), _____(day). Thank you very much for your willingness to hear more about the study.

7. The study is then not suited to your needs but thank you very much for your time.

8. Would you be willing to come with __________ (significant other) to the clinic one-half hour before your first visit with Dr. Fitzgerald to talk more with me about the study? (If yes, go to #6. If no, go to #9).

9. I appreciate that you feel you have enough to handle right now. Thank you for talking with me.

Appendix B

Subject Intake Form

Name:______________________________ Date:__/__/__

Age:________

Relationship to patient:
- ___ acquaintance
- ___ spouse
- ___ daughter/son
- ___ relative (specify:________________)
- ___ close friend

Have you ever had radiation therapy yourself?__ yes__no

Has anyone else close to you had radiation therapy?
__yes __no
If yes, who?

How long ago was that?

Did you accompany that person to any of their radiation treatments? ___yes ___no

Type of disease the patient is being treated for:
____

Time since diagnosis of the disease: ____________________

Please circle the highest grade in school which you have completed:

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 16+

Do you plan to accompany the patient to his/her next two visits and for at least one visit during his/her third week of treatment? ___yes ___no

To what extent do you agree with the following statement:

I prefer to be involved in what is happening to my spouse/relative/friend while he/she is going through radiation therapy.

Strongly Agree 1 2 3 4 5 Strongly Disagree

Appendix C

Informed Consent Form

I would like to invite you to participate in a research project designed to determine the effectiveness of several educational approaches to help the significant others of patients going through radiation therapy. Since it is not known which of these approaches is most effective, the friends, relatives or spouses of future patients will benefit if this project allows the researcher to identify those methods that are most successful.

If you agree to participate, you will be assigned in a random fashion to one of several intervention approaches. You will be asked to complete several short written instruments immediately prior to meeting with the physician for the initial visit and immediately prior to the patient's first treatment. You will also meet briefly with a research assistant during the third week of treatment and complete a questionnaire.

There will be no risk to you if you decide to be involved in the research project. It is possible that you may benefit from the educational interventions offered by understanding more about radiation therapy. A decision not to participate would in no way affect the medical care received in this clinic. Also, you are free to withdraw from the project at any time without any consequences to you or to the patient whom you accompany to treatment. All information obtained in this project will be kept anonymous and confidential. Participants will not be identified by name in any reports or publications.

CONSENT TO PARTICIPATE IN THE STUDY:
I have been informed of and understand the purpose of this project and its procedures. I wish to participate in this research project with the understanding that I may terminate my consent at any time and that I have the right to access the results of this research.

______________________________	________________
Subject Signature	Date

Please feel free to ask me any questions you may have about the project and your rights as a research subject. Please leave word with one of the clinic nurses that you wish to speak to me. Additionally, Dr. Fitzgerald and the clinic nurses are involved in the study and may be able to respond to your questions. Thank you very much for your willingness to be part of this study.

Helen Beattie, Principal Investigator

Appendix D

Radiation Therapy Knowledge Assessment

Instructions: Please complete the following knowledge assessment about radiation therapy. It will be most helpful to you if you do not guess so that the staff will be able to respond to all your questions. If you do not know or are not sure of an answer, just check the "don't know/not sure" choice. One of the clinic nurses will review the questions with you.

1. If a friend asked you about radiation therapy, would you say that: (check one)

( ) A. Radiation therapy is given to the whole body.

( ) B. Radiation therapy is given to a particular spot(s) in each patient.

( ) C. Radiation therapy is given exactly the same way for each patient.

( ) D. Don't know/not sure.

2. How would you explain a simulator machine? (check one)

( ) A. A simulator machine is for treatment.

( ) B. A simulator machine is for diagnosis.

( ) C. A simulator machine is used to outline the exact area of treatment.

( ) D. Don't know/not sure.

3. If your friend asked what radiation treatment does, would you say: (check one)

( ) A. It destroys most cells it passes through.

( ) B. It destroys the largest cells it hits.

( ) C. It destroys mainly tumor cells.

( ) D. Don't know/not sure.

4/10/86

4. If someone said, "People who get external radiotherapy become radioactive to others," what would you reply? (check one)

( ) A. Patients do not become radioactive and are not harmful to others.

( ) B. Patients become a little radioactive and may be harmful to others.

( ) C. Patients become very radioactive and are harmful to others.

( ) D. Don't know/not sure

5. How would you explain the purpose of the lead blocks used in treatment? (check one)

( ) A. The lead blocks make the radiation therapy beam more powerful.

( ) B. The lead blocks protect parts of the body which should not be treated.

( ) C. The lead blocks are put over the part of the body to be treated.

( ) D. Don't know/not sure

6. The average length of time radiation is being delivered during the treatment is: (check one)

( ) A. 30 to 90 seconds

( ) B. 3 to 7 minutes

( ) C. 10 to 15 minutes

( ) D. 15 to 20 minutes

( ) E. Don't know/not sure

4/10/86

7. If a person was having treatment to their stomach area, you would guess that they might: (check one)

( ) A. lose the hair on their head

( ) B. have nausea

( ) C. have trouble swallowing

( ) D. all of the above

( ) E. Don't know/not sure

8. If a friend asked you if radiation therapy treatment is painful, you would say: (check one)

( ) A. Yes, just in the treatment area.

( ) B. Yes, through the patient's whole body during the time of treatment.

( ) C. No, The patient doesn't have any pain during treatment caused by the radiation therapy.

( ) D. Don't know/not sure

9. Tumor cells: (check one)

( ) A. are able to repair themselves after being damaged by radiation therapy.

( ) B. are not easily damaged by radiation therapy.

( ) C. are not able to repair themselves after being damaged by radiation therapy.

( ) D. Don't know/not sure

10. Normal cells: (check one)

( ) A. are able to repair themselves after being damaged by radiation therapy.

( ) B. are not easily damaged by radiation therapy.

( ) C. are not able to repair themselves after being damaged by radiation therapy.

( ) D. Don't know/not sure

4/10/86

11. The marks which are put on the patient's skin are: (check one)

( ) A. large and permanent

( ) B. small and permanent

( ) C. are not permanent

( ) D. Don't know/not sure

12. A side effect of treatment which most patients will experience is: (check one)

( ) A. diarrhea

( ) B. vomiting

( ) C. tiredness

( ) D. all of the above

( ) E. Don't know/not sure

13. External radiation therapy is used to: (check one)

( ) A. kill all tumor cells

( ) B. shrink large tumors

( ) C. relieve pain

( ) D. all of the above

( ) E. Don't know/not sure

14. When a person is in the treatment room being treated with the radiation: (check one)

( ) A. they can be seen but not heard

( ) B. they can be heard but not seen

( ) C. they can not be seen or heard

( ) D. they can be both seen and heard

( ) E. Don't know/not sure

4/10/86

15. When going through a course of radiation therapy treatment,: (check one)

- ( ) A. very few patients continue working.
- ( ) B. many patients continue working.
- ( ) C. it is impossible to work during treatment.
- ( ) D. Don't know/not sure

16. A course of radiation therapy treatment lasts five days a week for: (check one)

- ( ) A. 5 weeks
- ( ) B. 6 weeks
- ( ) C. 7 weeks
- ( ) D. It is different for each patient
- ( ) E. Don't know/not sure

Name: ______________________________

THANK YOU FOR TAKING THE TIME TO FILL OUT THIS ASSESSMENT !!!

4/10/86

Appendix E

Mental Health Inventory

THESE NEXT QUESTIONS ARE ABOUT HOW YOU FEEL, AND HOW THINGS HAVE BEEN WITH YOU MOSTLY WITHIN THE PAST MONTH.

FOR EACH QUESTION, PLEASE CIRCLE A NUMBER FOR THE ONE ANSWER THAT COMES CLOSEST TO THE WAY YOU HAVE BEEN FEELING.

HOW HAPPY, SATISFIED, OR PLEASED HAVE YOU BEEN WITH YOUR PERSONAL LIFE DURING THE PAST MONTH?

	(Circle one)
Extremely happy, could not have been more satisfied or pleased	1
Very happy most of the time	2
Generally satisfied, pleased	3
Sometimes fairly satisfied, sometimes fairly unhappy.	4
Generally dissatisfied, unhappy	5
Very dissatisfied, unhappy most of the time	6

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HOW OFTEN DID YOU BECOME NERVOUS OR JUMPY WHEN FACED WITH EXCITEMENT OR UNEXPECTED SITUATIONS DURING THE PAST MONTH?

	(Circle one)
Always	1
Very often	2
Fairly often	3
Sometimes	4
Almost never	5
Never	6

55

DURING THE PAST MONTH, HOW MUCH OF THE TIME HAVE YOU FELT THAT THE FUTURE LOOKS HOPEFUL AND PROMISING?

	(Circle one)
All of the time	1
Most of the time	2
A good bit of the time	3
Some of the time	4
A little of the time	5
None of the time	6

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HOW MUCH OF THE TIME, DURING THE PAST MONTH, HAS YOUR DAILY LIFE BEEN FULL OF THINGS THAT WERE INTERESTING TO YOU?

	(Circle one)
All of the time	1
Most of the time	2
A good bit of the time	3
Some of the time	4
A little of the time	5
None of the time	6

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HOW MUCH OF THE TIME, DURING THE PAST MONTH, DID YOU FEEL RELAXED AND FREE OF TENSION?

	(Circle one)	
All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	59

DURING THE PAST MONTH, HOW MUCH OF THE TIME HAVE YOU GENERALLY ENJOYED THE THINGS YOU DO?

	(Circle one)	
All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	60

DURING THE PAST MONTH, HAVE YOU HAD ANY REASON TO WONDER IF YOU WERE LOSING YOUR MIND, OR LOSING CONTROL OVER THE WAY YOU ACT, TALK, THINK, FEEL OR OF YOUR MEMORY?

	(Circle one)	
No, not at all	1	
Maybe a little	2	
Yes, but not enough to be concerned or worried about it	3	
Yes, and I have been a little concerned	4	
Yes, and I am quite concerned	5	
Yes, and I am very much concerned about it	6	61

DID YOU FEEL DEPRESSED DURING THE PAST MONTH?

	(Circle one)	
Yes, to the point that I did not care about anything for days at a time	1	
Yes, very depressed almost every day	2	
Yes, quite depressed several times	3	
Yes, a little depressed now and then	4	
No, never felt depressed at all	5	63

DURING THE PAST MONTH, HOW MUCH OF THE TIME HAVE YOU FELT LOVED AND WANTED?

	(Circle one)	
All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	64

HOW MUCH OF THE TIME, DURING THE PAST MONTH, HAVE YOU BEEN A VERY NERVOUS PERSON?

	(Circle one)	
All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	65

WHEN YOU GOT UP IN THE MORNING, THIS PAST MONTH, ABOUT HOW OFTEN DID YOU EXPECT TO HAVE AN INTERESTING DAY?

	(Circle one)	
Always	1	
Very often	2	
Fairly often	3	
Sometimes	4	
Almost never	5	
Never	6	66

DURING THE PAST MONTH, HOW MUCH OF THE TIME HAVE YOU FELT TENSE OR "HIGH-STRUNG"?

	(Circle one)	
All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	68

DURING THE PAST MONTH, HAVE YOU BEEN IN FIRM CONTROL OF YOUR BEHAVIOR, THOUGHTS, EMOTIONS, FEELINGS?

	(Circle one)	
Yes, very definitely	1	
Yes, for the most part	2	
Yes, I guess so	3	
No, not too well	4	
No, and I am somewhat disturbed	5	69
No, and I am very disturbed	6	

DURING THE PAST MONTH, HOW OFTEN DID YOUR HANDS SHAKE WHEN YOU TRIED TO DO SOMETHING?

	(Circle one)
Always	1
Very often	2
Fairly often	3
Sometimes	4
Almost never	5
Never	6

70

DURING THE PAST MONTH, HOW OFTEN DID YOU FEEL THAT YOU HAD NOTHING TO LOOK FORWARD TO?

	(Circle one)
Always	1
Very often	2
Fairly often	3
Sometimes	4
Almost never	5
Never	6

71

HOW MUCH OF THE TIME, DURING THE PAST MONTH, HAVE YOU FELT CALM AND PEACEFUL?

	(Circle one)
All of the time	1
Most of the time	2
A good bit of the time	3
Some of the time	4
A little of the time	5
None of the time	6

73

HOW MUCH OF THE TIME, DURING THE PAST MONTH, HAVE YOU FELT EMOTIONALLY STABLE?

	(Circle one)
All of the time	1
Most of the time	2
A good bit of the time	3
Some of the time	4
A little of the time	5
None of the time	6

74

HOW MUCH OF THE TIME, DURING THE PAST MONTH, HAVE YOU FELT DOWNHEARTED AND BLUE?

	(Circle one)
All of the time	1
Most of the time	2
A good bit of the time	3
Some of the time	4
A little of the time	5
None of the time	6

75

HOW OFTEN HAVE YOU FELT LIKE CRYING, DURING THE PAST MONTH?

(Circle one)

Always	1	
Very often	2	
Fairly often.	3	
Sometimes	4	
Almost never	5	
Never	6	76

DURING THE PAST MONTH, HOW OFTEN DID YOU FEEL THAT OTHERS WOULD BE BETTER OFF IF YOU WERE DEAD?

(Circle one)

Always	1	
Very often	2	
Fairly often	3	
Sometimes	4	
Almost never	5	
Never	6	78

DURING THE PAST MONTH, HOW MUCH OF THE TIME DID YOU FEEL THAT YOUR LOVE RELATIONSHIPS, LOVING AND BEING LOVED, WERE FULL AND COMPLETE?

(Circle one)

All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	80

HOW OFTEN, DURING THE PAST MONTH, DID YOU FEEL THAT NOTHING TURNED OUT FOR YOU THE WAY YOU WANTED IT TO?

(Circle one)

Always	1	
Very often	2	
Fairly often	3	
Sometimes	4	
Almost never	5	
Never	6	81

HOW MUCH HAVE YOU BEEN BOTHERED BY NERVOUSNESS, OR YOUR "NERVES," DURING THE PAST MONTH?

(Circle one)

Extremely so, to the point where I could not take care of things	1	
Very much bothered	2	
Bothered quite a bit by nerves	3	
Bothered some, enough to notice	4	
Bothered just a little by nerves	5	
Not bothered at all by this	6	82

DURING THE PAST MONTH, HOW MUCH OF THE TIME HAS LIVING BEEN A WONDERFUL ADVENTURE FOR YOU?

(Circle one)

All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	83

HOW OFTEN, DURING THE PAST MONTH, HAVE YOU FELT SO DOWN IN THE DUMPS THAT NOTHING COULD CHEER YOU UP?

(Circle one)

Always	1	
Very often	2	
Fairly often	3	
Sometimes	4	
Almost never	5	85
Never	6	

DURING THE PAST MONTH, DID YOU EVER THINK ABOUT TAKING YOUR OWN LIFE?

(Circle one)

Yes, very often	1	
Yes, fairly often	2	
Yes, a couple of times	3	
Yes, at one time	4	86
No, never	5	

DURING THE PAST MONTH, HOW MUCH OF THE TIME HAVE YOU FELT RESTLESS, FIDGETY, OR IMPATIENT?

(Circle one)

All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	87
None of the time	6	

DURING THE PAST MONTH, HOW MUCH OF THE TIME HAVE YOU BEEN MOODY OR BROODED ABOUT THINGS?

(Circle one)

All of the time	1
Most of the time	2
A good bit of the time	3
Some of the time	4
A little of the time	5
None of the time	6

89

HOW MUCH OF THE TIME, DURING THE PAST MONTH, HAVE YOU FELT CHEERFUL, LIGHT-HEARTED?

(Circle one)

All of the time	1
Most of the time	2
A good bit of the time	3
Some of the time	4
A little of the time	5
None of the time	6

90

DURING THE PAST MONTH, HOW OFTEN DID YOU GET RATTLED, UPSET, OR FLUSTERED?

(Circle one)

Always	1
Very often	2
Fairly often	3
Sometimes	4
Almost never	5
Never	6

91

DURING THE PAST MONTH, HAVE YOU BEEN ANXIOUS OR WORRIED?

(Circle one)

Yes, extremely so, to the point of being sick or almost sick	1
Yes, very much so	2
Yes, quite a bit	3
Yes, some, enough to bother me	4
Yes, a little bit	5
No, not at all	6

93

DURING THE PAST MONTH, HOW MUCH OF THE TIME WERE YOU A HAPPY PERSON?

(Circle one)

All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	94

HOW OFTEN DURING THE PAST MONTH DID YOU FIND YOURSELF HAVING DIFFICULTY TRYING TO CALM DOWN?

(Circle one)

Always	1	
Very often	2	
Fairly often	3	
Sometimes	4	
Almost never	5	
Never	6	95

DURING THE PAST MONTH, HOW MUCH OF THE TIME HAVE YOU BEEN IN LOW OR VERY LOW SPIRITS?

(Circle one)

All of the time	1	
Most of the time	2	
A good bit of the time	3	
Some of the time	4	
A little of the time	5	
None of the time	6	96

HOW OFTEN, DURING THE PAST MONTH, HAVE YOU BEEN WAKING UP FEELING FRESH AND RESTED?

(Circle one)

Always, every day	1	
Almost every day	2	
Most days	3	
Some days, but usually not	4	
Hardly ever	5	
Never wake up feeling rested	6	97

Name:______________________________ Date: ____________________

Appendix F

Supplemental Subject Intake Data

Subject #__________

Patient's D.O.B.: ___/___/___

Severity of Patient's Condition:

1 = fully ambulatory and able to care for self

2 = moderately ambulatory and moderately able to care for self

3 = marginally ambulatory and marginally able to care for self

4 = non-ambulatory and dependent on others for care

Site Viewed Videotape:

1 = hospital

2 = home

Appendix G

Videotape Assessment

Below is a list of pairs of words. Please take a moment to think about the videotape you saw entitled, "Radiation Therapy: A Patient Perspective". Then, put a check on each line in the blank nearest to the word that best describes your feelings about the videotape.

1 2 3 4 5 6 7

I liked it___:___:___:___:___:___:___I disliked it

Easy to Understand___:___:___:___:___:___:___Hard to Understand

Clear___:___:___:___:___:___:___Confusing

Important___:___:___:___:___:___:___Not Important

Worthwhile___:___:___:___:___:___:___Worthless

Good Photography___:___:___:___:___:___:___Bad Photography

Useful for me___:___:___:___:___:___:___Useless for me

I learned a lot___:___:___:___:___:___:___I learned little

Calming___:___:___:___:___:___:___Upsetting

Answered my questions ___:___:___:___:___:___:___Did not answer my questions

This film had (check one):

( )too many facts
( )the right number of facts
( ) too few facts

Will this program make it easier or harder to talk with the doctors and nurses about illness and treatment of the person you have been accompanying to treatment?

( ) easier ( )harder ( )won't make a difference

Please explain:

What did you like best about the videotape program?

What would you suggest be done differently?

In what ways did the videotape help you?

Additional comments:

(1980, B. R. Cassileth; 1986, H. M. Beattie)

Appendix H

Clinic Experience Interview

1. How satisfied have you been with your experience here in the radiation therapy clinic?

2. On a scale of 1 to 10, 1 being not at all satisfied and 10 being very, very satisfied, how would you rate your experience?

3. What are your perceptions of the staff in the clinic?

4. Are there ways that they could have been more helpful to you?

5. Has there been anything they've done which has not been helpful to you?

6. Do you feel that you have been able to obtain all the information you wanted to know about what has been going on with ________________'s treatment?

7. Which person or people in the clinic would you go to to obtain information about ________________'s treatment?

8. Video Group Only:
   What did you think about viewing the videotape? Was it helpful? (If yes, ask: How? If no, ask: In what way(s) was it not helpful?)

9. Did it make it easier or harder to talk with ___________ (patient) about his/her illness? In what way(s)?

10. Any other thoughts about the experience?

Appendix I

Subject Inclusion Criteria

Inclusion:

1. Physically and mentally able to participate in the study.
2. Able to hear, read, and understand English.
3. Aware of the patient's cancer diagnosis.
4. 18 years of age or older.

Exclusion:

1. Had consistently accompanied another patient to treatment in the past.
2. Had personally undergone radiation therapy.
3. Patient had a common skin cancer (basal or squamous cell).
4. Patient had previously been through radiation therapy.

Appendix J

Clinic Experience Interview Summary

Summary of Comments

1. **How satisfied have you been with your experience here in the radiation therapy clinic?**

Usual:
- Very satisfied...she has been as comfortable as possible (cited repeatedly)
- Everything has been going quite smoothly
- All the people are all nice
- The clinic here is very nice. Helpful, which makes a lot of difference...You feel as if they are trying to help you.

Video:
- I think it has been very, very good. Very clear.
- Very impressive.
- Very (satisfied) because we just got over a very bad experience of chemotherapy before we came here.
- It was very quick and efficient and hardly any waiting.
- It seems that everyone is very nice and under standing.

2. **On a scale of 1 to 10, 1 being not at all satisfied and 10 being very, very satisfied, how would you rate your experience?**

Usual:- Average of 9.33; Range of 7-10
Video:- Average of 9.37; Range of 8-10

Reasons cited if rating was not a 10:
- It's just that she (the patient) felt that she couldn't ask questions and I don't know why. It's not her personality not to. I don't know whether it's the disease itself, or whether she can't speak about the cancer at that time.
- The johnnies could be big enough to fit my husband.
- Could have been on time more often
- There is a little bit of an uncomfortable factor with just being in a hospital.
- Even in the Olympics they don't give a 10...as far as I'm concerned, I probably should have said 10...

3. **What are your perceptions of the staff in the clinic?**

Usual:
- They are all capable and responsive to the patient's needs. They have made everything comfortable for her...There have been many questions we have asked. They answer them quickly and to the best of their knowledge.
- I think they are wonderful, every one of them.
- Very friendly and very helpful...any time there has been a question, it has always been answered.
- They are very helpful and very cheerful and willing to help you the minute you come in. They ask you how are you feeling. They are concerned about your welfare.
- Always smiling and pleasant and kind. Just beautiful.

Video:
- Just wonderful...they all have such a positive attitude.
- Well, they seem very efficient, and they all make you feel good...you seem to end up with people who come on to you with a smile and a welcome sort of situation.
- Very friendly, helpful and explained all of my questions.
- Very professional and courteous
- The nurse has come to me several different times to see how things have been. Again, it was very important and I haven't always had that happen where people have come and asked me how both you and your wife is feeling. A lot of times you don't tell everybody, especially the people getting the treatment, they are not really too open with it. In this particular case, my wife is not too open so with the nurse coming to me and asking me. I think that's great. Interviewer: So you had a feeling that she cared about how you were feeling too? Response: Not only my wife, but also myself.
- I think that they are caring, and this is without exception, in each place they help you along.

4. **Are there ways that they (the staff) could have been more helpful to you?**

Usual:
- None whatsoever (cited repeatedly).
- I've called twice. Once when he had a very bad sore throat and I called yesterday because he

has been coming very sick to his stomach and right away they put me through to the nurse and she told me what to do, what it was and that she would talk to him when he got here...very, very nice.
- Been on time.

Video:
- Registration process upstairs sited as taking a long time
- Not really because I don't know anything about radiation in the first place, so even if they did omit something, I wouldn't know it.
- No, with the planning that they have done as well as the information that was fed to us both by Dr. Fitzgerald on the first visit as well as the videotape, I think all the information was pretty well up front so that we understood exactly what was going to happen.

5. **Has there been anything they've done (the staff) which has not been helpful to you?**

Usual:
- No (cited repeatedly)
- No. The only thing that has bothered her (the patient), but it was covered, was when different people talk about their treatments and their side effects (in the waiting room). She says that she knows it wasn't supposed to bother her, but it did.

Video:
- No (cited repeatedly)
- 1 instance cited when the van did not pickup the patient because of bad weather.

6. **Do you feel that you have been able to obtain all the information you wanted to know about what has been going on with ________________'s (the patient's) treatment?**

Usual:
- Adequate information cited repeatedly.
- In my wife's particular case, it's a severe case, well any cancer is a severe case as far as any emotional effect it might have upon people, but the nurses informed her and I was sitting in on it. Basically they covered as much as they possibly could on it and I don't think they left anything untouched as far as side effects are concerned.
- Yes, very much so. I feel at ease about that.
- Well, they told me about the simulation. I didn't realize that the simulation, the mapping of the skull. Well, as far as their telling me what the reduction of the tumor was or will it

grow again, they haven't given me any of that information.
- Oh no, no, no. Well, I know a lot more than I did before. People in the bus talk about it and they wonder about it. Some of them have markings on the areas of radiation. One girl had it on yesterday, and it is off today, and she was wondering about that. Just little things. Interviewer: Now let me get this straight. Then there are things that are going on there with his treatment that you don't really understand why they are doing it? Reply: No, only what I hear from people in the bus...(but reports that she has talked with Dr. Fitzgerald and feels free to ask questions of the nurse) Subject concludes: "I don't expect to understand radiation really, you know, I wouldn't expect that".
- Well, I think so. My wife is usually the one that asks. Because she is the one that wants to know more about it. She tells me, you know. No complaints as far as I know.

Video:
- Adequate information cited repeatedly.
- That videotape was excellent and that was really good. And I had read, when my mother came in March, she had picked up a bunch of pamphlets, and I had read through those and stuff just for my own information. And that I think is very helpful. At least you know so you can kind of prepare for those kind of things. I learned a lot from that tape--it was great.
- Yes I have. Starting with the video, it gave me a lot of input.

7. **Which person or people in the clinic would you go to to obtain information about __________'s (the patient's) treatment?**

Reported results reflect the **first** person cited.

Usual: Nurse - 6 subjects
Referring Specialist - 3 subjects

Video: Nurse - 2 subjects
Radiologist (MD) - 5 subjects
Friend with medical background - 1 subject

8. **Video Group Only: What did you think about viewing the videotape? Was it helpful? (If yes, how? If no, in what way was it not helpful?)**

- Oh, that was great. You know, I kind of thought, wouldn't it help the patient to see that too...It is so informational, and it is very candid, too. The people, you know, were very honest. It was great. I think that was an excellent tape. You know, you see a lot of documentary type things that are -- OK...this is the machine we are going to use and this is how...yes, that is informational, too, but it is not as personal and this is very personal. Interviewer: Did it feel long to you? Response: No, not at all, not at all. You know, I would have liked more...You know, they showed the guy going for his treatment one day. If there were more of that, like you know, maybe people who had different things, because I know that different people have different kinds of treatment.
- I thought it was excellent.
- Well, I thought it was very informative. I had no idea what radiation was except from word of mouth from this one and that one, and the few that I talked with ..they felt they had stomach aches and nausea...another party...thinks that he got burned, and the burn caused him more pain than he had before, but having that explained, not only on the video but through the doctor, it makes me question if...it is just a situation where reaction to the radiation was different in one person than another. I knew nothing about radiation. Yes, definitely, it seemed like it was getting it straight from the horse's mouth, so to speak. (Wife chose a lumpectomy rather than having a mastectomy)...and so it encouraged our decision by watching the video...pretty apt to be OK, and that was a big plus.
- Interviewer: Did you learn new things from the videotape. Yes, for instance, one of those questions about the block thing...Well, I knew when you went to the dentist, you put the apron on, but I had no idea what they were talking about, the block. I have never had any experience with anyone in my family having to use this. That (video) sort of explained some things and made it a little clearer.
- I liked the videotape except for I didn't like the idea that the patients spoke enough about their illness. I'd like the whole story. Maybe

using fewer patients and I would like the story from start to finish, how they first got the disease and how they first thought that they were sick, what the symptoms were in the beginning. I did like the people. I thought they were very nice, very informative to me. I had never had any contact with cancer before and I enjoyed the tape.

-We saw it twice and of course the first time we saw it I didn't know what to expect to see and it answered a lot of unanswered questions. I mean I didn't really know how to accept this to begin with and answered a lot of thoughts that I had as to what the procedure would be...I thought it was well done...I felt that my mind was more at ease. Definitely more at ease (after viewing the videotape).

-I thought it was great...almost everything that you would want to know about.

-It's kind of funny because when we first got it, my wife had watched it and even though I wanted to, I didn't. I brought it back and turned it in and Ann talked to me and asked what did you think about the video. I said truthfully, I didn't watch it and she said take it back with you and make sure that you watch it...After I watched it, I was very happy that I did...feeding the information to you, knowing how other people are affected and just understanding it. Interviewer: You watched it once? Response: I watched it 3 times as a matter of fact.

-I think it helped to know what she was going through, if she didn't feel good about something, if it was radio connected or just something that was an upset from serves, and I think that that was a big plus.

9. **Video Group Only: Did viewing the videotape make it easier or harder to talk with ____________ (patient) about his/her illness? In what way?**

-Oh yes, this is how the film helped. We were able to communicate, we knew what we were talking about. She had been through it and I saw it.

-We never had any difficulty talking about it at all. (cited by several subjects)

-Interviewer: Did this tape and your experience help you and your wife to talk about this experience more candidly? Response: Oh yes, she has accepted the fact and talks about it, talks to her friends about it. I think a lot of the questions we've been able to answer has been from the video. We were more involved with it through the video than we would have been just in conversations, say with the doctor, because pictures show a lot, what do they say...they are worth a thousand words. (Viewed at home twice - first with patient and his son's family and then again with his daughter and her family)

-When we were talking in the car on the way home, she (the subject's mother) said, 'Oh, what was this tape about?', and I told her, you know, all the stuff. 'I didn't know that, nobody told me that' (the mother replied). It was very informational for me, and yeah, I think it made her more able to talk to me about, you know, what was going on.

-Interviewer: Do you think that your experience here has contributed to being open about it? Response: Oh, definitely, yeah. By both watching the tape and being together at each meeting... That is the biggest thing. Caring persons share what each other is going through.

10. **Any other thoughts about the experience?**

Usual:-Well, I'd give them an A+ rating.

-The whole staff here has been absolutely wonderful.

-If I was younger, I may have some different answers. When you get old like me, you get used to these things.

-When I was filling out the questionnaires, some of the answers I put I felt like I should be writing an essay because I have two kids, because I know one of them had something to do with "can you remember the last time you got a good nights sleep". I have two kids so...

-After they told me the discouraging news in the beginning, anything now is uphill. We feel and we've heard others that have been here and are on the road to recovery so we feel very confident.

-Of course we had to wait some days as much as 45 minutes upstairs waiting and I find it tiring, with all the people coming in and registering (mentioned by 1 other subject).

-I know when the word cancer now, you don't feel numbstruck, you know. You understand that there could be a cure and that you could learn to live with it. Before, you hear the word and you are numb. But now with the information, you have visual evidence of it...I was amazed that they would come in here and joke, which is good. In the old days it was just morose, and...sweep it under the rug.

Video:-Just to get to give people more information... cause it is sometimes hard to pick up a book and read, you know, just read information about it. But when you see somebody who is talking, you know, like a normal person...'yeah, well, then they did this to me', and they explain it like anybody would when they were talking, but not like a book, like ...'oh, then this machine will lower onto...', you know, that is very hard to understand.

-I got a lot from the film and I feel very comfortable coming here. The personnel here are so positive and cheerful, and we don't dread coming in at all.

-I think that the whole thing is a long drawn out affair, but I think that once you find out that you've got cancer and there is still a chance to live a full life by spending 2-3 months effort, or whatever, you want to put into it, it is good.

-I think that the cancer treatment is more hopeful than I thought it would be. Before I thought when you had cancer, that was the end, but this gave me a feeling that there is hope for the person with cancer and a lot of it can be cured.

-Nobody likes to have what they do have and I don't think you can prevent it, if it's going to happen, it's going to happen and you just have to learn as much about it and become more knowledgeable of it and work with the people involved and hope that everything is going to be OK which in our particular case seems to be heading in that direction.

-If it wasn't for the van, I don't know what we would have done. We would have had to try each day to get somebody to bring us down. So, that really is great.

Appendix K

VIDEOTAPE ASSESSMENT COMMENTS

Descriptive Question Summary

What did you like best about the videotape program?

- The format - rather than being just informational it showed real people who shared their experiences.
- All the patients appeared very comfortable with the process and confident with their doctors, nurses and technicians.
- Watching the videotape made it easier to understand what radiation therapy is all about.
- The patients seemed to take their radiation treatments in a calm and relaxed manner.
- The optimism of the patients that were in the film plus the ease that they explained their own stories.
- I liked the people talking about their illness.
- Liked everything.
- It explained a lot of things that I think everyone has questions on radiation.
- I understood what procedures my wife was undergoing. And we could talk about it. (What) I liked best was the explanation of the machine and marking.
- Very informative - giving information so that you can understand what is happening.
- It was easy to understand.
- It was interesting hearing from patients as well as M.D.s and nurses what is involved when one has radiation treatments.
- Real reactions from real patients. The patients conveyed positive attitudes which I feel must be reassuring to new patients viewing the film.
- It told clearly what my husband's treatments would be and satisfied my curiosity.

What would you suggest be done differently?

- Not a thing. (5)
- Probably using fewer people - each one telling their story from start to finish.
- Maybe you could view the film before the first visit.
- OK as it is.
- Extend the talking over of the treatments.

In what ways did the videotape help you?

- It is helpful to know that there are people who have had successful experience(s) with radiation therapy.

- In familiarizing me with the actual treatment and how it is set up and administered.
- It helped to understand what this therapy is all about.
- Explained about soap, etc. Also reviewed the procedures that Mary went over with us at the second appointment.
- It showed me that there is hope for people with cancer.
- Helped me in all the explanations.
- It told me a lot about the radiation and what to expect as possible reactions of my friend.
- Understanding
- Ease my mind
- Explaining what is involved and what effect it has on the cancer.
- It was positive, reassuring and educational
- It cleared my mind of what radiation is and took a "fear" from my mind.

Additional comments:

- The videotape is most helpful because the information is coming from people who are undergoing or have undergone radiation therapy, so you get the patient perspective. I found the doctor, nurses and technician to be very informative and thorough and had most of my questions and concerns addressed prior to viewing videotape but it is still nice to have a patient's point of view.
- I think this videotape is a big help to new patients understand what is about to take place concerning treatment.
- Like the kindness of the doctor and nurses to myself and my husband. It helps a lot.
- I personally have already had chemo but was not familiar with radiation.
- Everyone connected with the radiology department are so positive, cheerful and wonderful.

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