

The Interpersonal Dynamics of Cancer: Problems in Social Relationships and Their Impact on the Patient¹

One in four Americans develops cancer and two out of three families are touched by it (American Cancer Society, 1978). Even more alarming, the incidence of cancer has been rising for many years, yet little progress has been made in discovering its primary causes. In a substantial proportion of cases cancer is fatal. In fact, next to heart disease it is the most frequent cause of death in the United States (American Cancer Society, 1978). However, cancer is no longer synonymous with death; for many it is an acute or chronic disease that can be treated.

A notable feature of cancer as compared to other life crises is that it is usually *not* a single event, but a series of events that may last over several years. At the beginning there is the initial diagnosis and surgical, radiation or chemotherapeutic treatments. Later on, periodic checkups are necessary, and recurrence, extended treatment, remissions, metastases (disease spread), or a terminal phase may follow. Indeed, the ultimate outcome is typically unclear for long periods of time. Thus, considerable ambiguity

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usually accompanies the other physical and psychological stresses of the disease.

These factors—the prevalence of cancer, its rank as a major cause of death, its potential to be treated over long periods of time, and the ambiguity surrounding the outcome—suggest that its psychological aspects merit attention. How do individuals live and cope with the disease on a day-to-day basis? What difficulties are typically encountered by the person with cancer? What factors influence the patient's psychological distress and quality of life? A person's psychological reactions to the disease are not only important in their own right but also may influence the patient's physical condition and ultimate prognosis (Derogatis, Abeloff, & Melisaratos, 1979; Rogentine, van Kammen, Fox, Docherty, Rosenblatt, Boyd, & Bunney, 1979; Weisman & Worden, 1975). For this reason as well as for those just mentioned, greater knowledge of the psychological aspects of cancer is greatly needed.

This chapter focuses on one psychological aspect of living with cancer: the effect of the disease on the patient's interpersonal relationships, and the ultimate impact of these relationships on the patient's emotional adjustment to the illness. One factor that has influenced our approach to this problem is our former work, as social psychologists, on the question of how victims of uncontrollable life events are treated by others. As we have detailed elsewhere (Coates & Wortman, 1980; Dunkel-Schetter & Wortman, 1981), people undergoing life crises often experience a strong desire for social support. Furthermore, there is evidence that support from others can be highly beneficial in ameliorating the effects of negative life events. Yet others are often threatened and made uncomfortable by the victim's status and are therefore unable or unwilling to provide effective support. In fact, the more unfortunate the victim's plight or the more distress the person shows, the more threatened, uncomfortable, and rejecting others may become (see Coates, Wortman, & Abbey, 1979, for empirical evidence on this point). Thus, individuals in greatest need of social support may be least likely to get it.

To our knowledge, this social psychological "victimization" perspective has not been applied to the social environment of the cancer patient. Yet, because of the intense fears and the stigma associated with the disease (Public attitudes toward cancer, 1980), those who have cancer may be especially likely to experience problems in their interpersonal relationships. Few investigations have carefully probed the interpersonal problems experienced by cancer patients, but numerous authors describe them (e.g., Cobb & Erbe, 1978). For example, Vachon, Lyall, Rogers, Formo, Freedman, Cochrane, & Freeman (1979), Parkes (1974), and Abrams (1966) have each discussed problems between cancer patients and physicians, and Cobb (1956) discusses difficulties with nurses. Investigations on the impact of cancer document varying degrees of family and marital problems

(Greenleigh & associates, 1979; Lee & Maguire, 1975; Meyerowitz, Sparks, & Spears, 1979; O'Malley, Koocher, Foster, & Slavin, 1979) resulting from cancer. The existence of problems in at least some proportion of families when a member has cancer is further substantiated in anecdotal and data-based descriptive accounts (Dyk & Sutherland, 1956; Kaplan, Grobstein, & Smith, 1976, Parkes, 1972b). In addition to difficulties in relationships with family and physicians, problems with friends, acquaintances, and social life seem to occur in some cases (Greenleigh & Associates, 1979; O'Malley *et al.*, 1979; Silberfarb, Maurer, & Crouthamel, 1980; Sutherland, Orbach, Dyk, & Bard, 1952). Particularly high rates of interpersonal difficulties have been demonstrated to occur among adolescents with cancer, probably because of the added problems of this life stage (Boeck & Leventhal, 1979; Moore, Holton, & Marten, 1969; Tebbi, Tull, & Koren, 1980).

Especially notable in the literature is the frequent mention of communication problems (Cobb & Erbe, 1978; Harker, 1972; Klagsbrun, 1971; Krant, Beiser, Adler, & Johnston, 1976; Kubler-Ross, 1969; Spiegel, 1979; Wellisch, Mosher, & Van Scoy, 1978; Winder, 1978). For example, Gordon, Freidenbergs, Diller, Rothman, Wolf, Ruckdeschel-Hibbard, Ezrachi, & Gerstman (1977) asked 136 patients with breast, lung, and sarcoma cancers whether or not they had experienced any of 100 problems. Of the 20 problems most frequently noted by all patients, seven were of an interpersonal nature (e.g., "people acting differently after the cancer"), and three of the seven were explicitly concerned with communication issues (e.g. "communication about the cancer with friends difficult," "discussing future with family difficult"). In another study of 33 outpatients, Bean, Cooper, Alpert, & Kipnis (1980) found that over half of the comments made by subjects dealt with the communicative aspects of their relationships. We know of no studies that have compared cancer patients with other populations, so it is not clear whether they experience greater interpersonal distress than do other ill populations or well individuals. However, the evidence noted earlier suggests that such problems are reported frequently enough to merit attention.

A second factor shaping our approach in this chapter is our personal experience with cancer patients. For the past 5 years the authors have been serving as facilitators in peer support groups for cancer patients and their family members. These groups are part of a national organization called Make Today Count (see Make Today Count, 1977; Peebler, 1975; Pellman, 1976), the purpose of which is to provide a setting where patients and family members can engage in open communication about problems encountered in attempting to live with cancer.

Although it is not clear how representative the group members are of the total population of cancer patients, we have been struck by the high frequency of interpersonal problems reported at group meetings. People

frequently report being upset and bewildered by the responses of family members and friends. For example, group participants often indicate that spouses show an unwillingness to acknowledge the disease and its ramifications and to discuss these with them. Perceived avoidance by friends, and awkwardness and tension while in the patient's presence are also common themes. In addition, group members report that others are generally intolerant of their negative affect, close off discussion of issues the patients would like to pursue, and minimize the importance of these issues.

AN ANALYSIS OF THE INTERPERSONAL DYNAMICS OF CANCER

A Brief Overview

A person diagnosed with cancer is likely to be highly fearful and uncertain. The intensity of these feelings may lead patients to worry that they are coping poorly or losing their grip on reality. Many patients experience a need to clarify the meaning of their responses to the illness in order to learn whether their reactions are reasonable and normal. People with cancer also experience intense needs for emotional support from others. However, communication barriers make it especially difficult for cancer patients to obtain the clarification and support they need.

The reactions of others who are prominent in the life of the patient (family, friends, health care personnel) are likely to be determined by two factors: by their feelings about the patient and the illness, and by their beliefs about appropriate behaviors to display when in the patient's company. Although their feelings about the patient's illness are largely negative, they believe that they should remain positive, optimistic, and cheerful in their interactions with the patient. This contradiction may result in behaviors that are unintentionally harmful to the patient, including (a) physical avoidance of the patient; (b) avoidance of open communication, especially about the disease and its effects; and (c) contradictory or inconsistent behaviors.

The person with cancer often interprets these ambiguous and negative actions as rejection at the very time when communication with and support from others is especially important. He or she may try subsequently to increase the support and attention received from others by one of two opposite strategies: exaggerating and stressing difficulties, or hiding problems from others, thus conveying the impression that he or she is coping well. Unfortunately, these solutions only serve to make it more difficult for others to know how to react to the patient and may therefore exacerbate their interpersonal problems rather than solve them. This analysis of the cancer pa-

tient's situation is described in more detail with reference to relevant evidence in the following subsections.

The Cancer Patient's Situation

Fears and Uncertainties

The individual who has just been diagnosed with cancer is likely to be profoundly fearful and uncertain about many things. An environment that was previously at least tolerable has now become increasingly unpredictable and threatening. Former assumptions and beliefs about the world and one's self are brought into question. The person is confronted with a web of fears, including fear of pain, of recurrence, of progressive deterioration, of dependency on others, and of death (Davies, Quinlan, McKegney, & Kimball, 1973; Hackett & Weisman, 1969; Katz, Weiner, Gallagher, & Hellman, 1970; Lewis & Bloom; 1978-1979; Meyerowitz, 1980). Patients worry, for example, about whether the doctors have been honest with them, whether they are receiving the best care, and how their illness will affect their families. They are also forced to contend with a variety of physical changes and problems, which may include pain, energy loss, disfigurement, nausea, hair loss, and unpleasant odors. Clearly such things can be unsettling and can have a profound effect on the patient's self-concept. Countless descriptive sources and some empirical work corroborate the contention that the diagnosis of cancer elicits terror and uncertainty about the future (e.g., Greenberg, 1961; Milton, 1973; Orbach & Tallent, 1965; Quint, 1965; Rollin, 1976; Sutherland *et al.*, 1952).

Within the context of this fear and uncertainty, the person with cancer is often called upon to function more competently than ever before in making a multitude of decisions. These may range from questions about what hospital to enter, which physician to contact, and what treatment to have to questions about if and what to tell their children, friends, and coworkers. Many patients are overwhelmed by the number and complexity of decisions to be made. Although these decisions are similar to those that people make in everyday life, they are linked to graver consequences for the cancer patient. Furthermore, the person is usually emotionally and physically less able to tackle them. In addition, a large number of these decisions concern matters with which the patient has no expertise or prior experience. Because of the considerable ambiguity within the field of medicine about how to treat certain types of cancer, there are often no clear-cut answers to some of the problems facing the patient. Thus, it will frequently be impossible for the patient to feel confident that the chosen alternatives are the best ones. Evidence that cancer patients experience anxiety and emotional distress is consistent with the above description of patients' fears and uncer-

tainty. (Achte & Vauhkonen, 1971; Chesser & Anderson, 1975; Craig & Abeloff, 1974; Forester, Kornfeld, & Fleiss, 1978; Hinton, 1963; Lee & McGuire, 1975; Lewis, Gottesman, & Gutstein, 1979; McGuire, 1978; Meyerowitz, *et al.*, 1979; Morris, Greer, & White, 1977; Parkes, 1972b; Peck, 1972; Silberfarb, *et al.* 1980).

A Need for Clarification and Support

Because of the uncertainties they face and because their sense of self is threatened, many people with cancer experience intense needs both to clarify what is happening to them and to be supported and reassured by others. Concerning clarification, the intensity of their fears and uncomfortable feelings may lead many cancer patients to worry that they are coping poorly or are losing their grip on reality. They experience a need to understand the meaning of their responses. Are their reactions to the crisis reasonable or "normal"? How *should* they be responding? How long will their fears and anxieties last? There are at least three distinct ways that patients may gain clarification: by receiving comparison information, by being encouraged to discuss feelings openly with others, and by interacting with others whose experience enables them to provide feedback to the patient about the meaning of his or her responses to cancer. Each of these is elaborated upon in the following discussion.

One way to learn more about the meaning and appropriateness of various behaviors is through gaining relevant comparison information. As Festinger (1954) and Schachter (1959) have pointed out, confusion and ambiguity can often be resolved through social comparison. For example, a patient can learn from exposure to others that it is normal to become angry or depressed after diagnosis, to fear recurrence, and to be avoided by some of one's former friends. Comparison information can be obtained from educational materials (articles, books, or specially prepared pamphlets about cancer, films or television programs, lectures, symposia or public meetings), or from face-to-face encounters with other patients. Some of these sources may provide general information about how most cancer patients react to certain treatments or problems; other sources include individual accounts or "case studies" in which a patient describes his or her personal reactions to the disease. All of these can help the patient clarify his or her feelings by providing information about problems typically encountered, common or normal reactions, and strategies which might be employed to cope with them. However, personal accounts may be the most effective in influencing patients' beliefs because they are more vivid and thus more involving (Kahneman & Tversky, 1973; Nisbett & Borgida, 1975, Ross, 1977; and Sanders & Kardinal, 1977 on cancer specifically).

Few studies have probed patients' needs to clarify their responses. However, there are indications that under many circumstances, patients

and family members would like to receive more information about treatments, side effects, and other reactions to the disease than they are normally given (Bloom, Ross, & Burnell, 1978; Cassileth, Zupkis, Sutton-Smith, & March, 1980; Greenleigh & Associates, 1979; Henriques, Stadil, & Baden, 1980; Messerli, Garamendi, & Romano, 1980; Krant & Johnson, 1977-1978; Morris *et al.*, 1977; Sheffer & Greifenstein, 1969). For example, Messerli *et al.* (1980) report that when breast cancer patients were asked if there were unanswered questions concerning their treatment, 86.2% answered in the affirmative. A survey of 15 hospitals by these same investigators revealed that information on stages of breast cancer, choices of surgery, postoperative therapy, prosthesis information, reconstructive surgery, and personal counseling was conspicuously absent. Similarly, in a survey of information preferences among cancer patients, Cassileth *et al.* (1980) found that a large majority of patients desired information on such issues as the possible side effects of treatment (98.0%), whether all parts of the body are involved (94.9%), and exactly what the treatment would do inside the patient's body (96.3%). There is also empirical evidence to suggest that such information is beneficial to the patient. In one study, women who were provided with information about breast cancer surgery were subsequently more satisfied than those who were not (Blum, 1980). Similarly, Gerle, Lundin, and Sandblom (1960) report that a group of cancer patients who received all the facts regarding their illness showed considerably less anxiety and depression and a resultant decrease in the use of psychotropic drugs, compared with a group told little or nothing regarding the nature of their disease.

A second way that patients can help to clarify the meaning of their feelings is to discuss them frankly and openly with a sympathetic listener. Articulating one's fears and feelings may be the first step in understanding them and in working out strategies for coping with them. By allowing the patient to express his or her concerns, by acknowledging these concerns, and by acting as a "sounding board," relatives, friends, or health care personnel can help the patient to interpret and manage his or her experiences.

Some evidence suggests that patients would like additional opportunities to discuss their problems (Coblner, 1977; Greenleigh & Associates, 1979; Kleiman, Mantell, & Alexander, 1977). For example, Mitchell and Glicksman (1977) conducted an interview study of 50 cancer patients undergoing radiation therapy. Only 22 patients were able to identify a person with whom they could discuss their emotional problems, and 86% of the patients wished to be able "to discuss the situation more fully" with someone. Despite apparent interest in discussion with others, the value of it is not well documented. As we discuss later, however, the available evidence suggests that it is advantageous (Binger, Ablin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969; Coblner, 1977; Cohen, Dizenhuz, & Winget, 1977; Derogatis *et al.*, 1979; Kaplan, *et al.*, 1976; Kellerman, Rigler, Siegel, &

Katz, 1980; Spinetta, Swarner, & Sheposh, 1981; Vachon, Freedman, Formo, Rogers, Lyall, & Freeman, 1977; see also Silver & Wortman, 1980, for a review).

A third, and perhaps best, way for patients to clarify their feelings is to have the opportunity to discuss these feelings and personal reactions with others who can provide feedback about their meaning and appropriateness (e.g., other cancer patients who have shared many of the same experiences as the patient, or health care professionals who have had considerable experience with the patient's disease). Because this approach includes both exposure to comparison information and opportunity to express one's feelings, it would seem to have an advantage over either of these alone.

Although the evidence is not entirely consistent (see Mitchell & Glicksman, 1972),² it suggests that patients generally wish to talk with others with the same disease or problems (Binger *et al.*, 1969; Bozeman, Orbach, Sutherland, 1955; Messerli *et al.*, 1980; Sanders & Kardinal, 1977). In one study, meetings with other cancer patients were among the most frequently mentioned services that cancer patients felt should be provided. Of those who had been personally offered the opportunity to meet with other cancer patients for support, 52% had taken advantage of it. In fact, more than one-third of the men and women surveyed indicated an interest in volunteering to help others through a peer support program for cancer patients (Greenleigh & Associates, 1979).

There is also some research to suggest that discussions with similar others are beneficial (Binger *et al.*, 1969; Bozeman *et al.*, 1955). For example, Bozeman *et al.* (1955) reported that other parents with leukemic children "were regarded by most mothers as the most important source of emotional support [p. 15]." In one study, Parkes (1979a) found that individuals dying from cancer in hospitals or a hospice frequently reported becoming acquainted with other patients. Such interactions were seen by the majority of those who had them as helpful and by very few as upsetting.

The uncertainties and fears of the person with cancer are likely to result in an enhanced need for social support as well as an increased need for clarification (Lieber, Plumb, Gerstenzang, & Holland, 1976; Schwartz, 1977; Thomas & Weiner, 1974; Vachon, *et al.* 1979). As the patient contends with the prospect of a shortened life, unpleasant and possibly mutilating treatments, and physical deterioration, the need for support may grow stronger. In fact, one of the many fears patients have during the early stages of cancer is that they will be rejected and abandoned by loved ones (Sutherland & Orbach, 1953).

Several studies have provided evidence that perceived support is

²The majority of the patients in Mitchell and Glicksman's (1977) study felt that it would be undesirable to spend additional time with other patients, but almost all of the patients who felt that way had not engaged in open discussions with other patients in the waiting room. Most of the patients who had discussed their problems openly in the waiting room expressed a desire to spend additional time with other patients to discuss common problems.

associated with positive outcomes such as improved emotional adjustment among cancer patients (see, e.g., Jamison, Wellisch, & Pasnau, 1978; Lewis & Bloom, 1978-1979; Weisman & Worden, 1976; see Meyerowitz, 1980, for a review). A positive relationship between social support and numerous outcome measures (e.g., physical health, emotional well-being) has also been found among individuals undergoing other life stresses (see Cobb, 1976; DiMatteo & Hays, 1980; or Silver & Wortman, 1980, for reviews). In most cases, these studies are correlational, so that it is unclear whether social support actually causes better physical and psychological adjustment. One alternative explanation for these findings is that stressed or victimized individuals who are poorly adjusted might alienate members of the support network to a greater degree than those who are doing poorly (and consequently receive less support). Alternatively, those who are doing well may be less critical in the judgments they make about the adequacy of their social support network. These and other ambiguities could be resolved by longitudinal research that assesses social support at one point in time as a predictor of subsequent distress or physical deterioration. In one such study (Vachon, 1979a), social support was associated with better long-term adjustment among both cancer patients and the bereaved. A causal relationship between support and effective long-term adjustment could also be established by intervention studies in which participants are assigned to treatments that mobilize their support system or supplement the support available to them (e.g., Bloom, *et al.* 1978). (For a more detailed discussion of the social support construct, including various types and components of social support, possible mediating mechanisms through which social support may influence outcomes, and possible deleterious effects of behaviors intended to be supportive, see Antonovsky, 1979; Caplan, 1979; Cobb, 1976; Cohen & McKay, in press; DiMatteo & Hays, 1980; Heller, 1979; House, 1981; Kahn & Antonucci, 1980; Silver & Wortman, 1980.)

Barriers to Social Validation and Support

Although persons diagnosed as having cancer may have many needs that could be satisfied through social interaction, they are likely to have difficulty in meeting these needs. In most cases, cancer patients have limited access to others suffering from comparable problems. They may be exposed to newspapers and other media coverage of cancer; however, such presentations may be biased toward patients who have a positive attitude and who are coping well. Other patients may be encountered by chance in a hospital waiting room or doctor's office, but these settings are ones in which only superficial exchanges are likely to take place.

In fact, three investigations confirm that cancer patients and mothers of children with leukemia interact very little with one another in hospital waiting rooms (Hoffman & Futterman, 1971; Mitchell & Glicksman, 1977; Peck & Boland, 1977). The majority of these patients spent no time talking

to other patients during waiting periods before treatments or spoke only of "trivial subjects" during this time. This type of exposure to others with cancer could actually be detrimental, since it could lead patients to the erroneous conclusion that most people have few problems in coping with cancer and that their own confusion, doubts, and fears are deviant and abnormal. This research suggests that intimate discussions between cancer patients are unlikely to occur spontaneously. Moreover, because cancer is such a stigmatizing disease, many patients may feel inhibited about seeking out other cancer patients or publicly identifying themselves as such. For these reasons, patients are usually forced to rely on dissimilar others such as health care professionals, family members, and friends for validation and support. This is unfortunate, since other cancer patients are in a better position to provide consensus information that the patient's reactions are normal and understandable.

Although family, friends and health care professionals are more likely to be available to the patient than are other people with cancer, two particular factors may inhibit the patient from approaching these people and discussing their feelings. First, cancer patients may fear that open discussion of their feelings about the illness will upset or hurt others. This strategy of protecting others may be especially strong toward family members, because they are perceived by the patient as being already overburdened by their illness (Bean *et al.*, 1980; Harker, 1972; Schwartz, 1977). Second, patients may believe that it is inappropriate to express their feelings or concerns to others, particularly their doctors. These beliefs may occur both because patients feel that doctors are too busy for such conversation (Mitchell & Glicksman, 1977) and because they believe that bringing up one's concerns will elicit a negative reaction from the doctor. In fact, being silent, passive, and accepting is the perceived role of a "good patient" (Greenberg, 1961; Tagliacozzo & Mauksch, 1972; Taylor, 1979).

Although the specific reasons have not been explored, there is evidence that the needs of cancer patients for social interaction are frequently not met by dissimilar others (Bard, 1952; Bean *et al.*, 1980; Cohen *et al.*, 1977; Gordon *et al.*, 1977; Jamison *et al.*, 1978; Krant & Johnson, 1977-1978; Mitchell & Glicksman, 1977; Sanders & Kardinal, 1977; Vachon *et al.*, 1977; Wellisch, Mosher, & Van Scoy, 1978). The following analysis of the reactions of others to the cancer patient offers some additional perspectives on why this occurs.

Reactions of Others to the Person with Cancer

What types of behavior do cancer patients generally elicit from others? A person's behavior toward the patient is likely to be influenced by two factors: by a complicated set of feelings and attitudes toward the cancer pa-

tient, and by prior assumptions and beliefs about how one should behave when interacting with the person. Each of these factors is described in more detail in the following discussion. We then argue that the behaviors people see as desirable are often discrepant with their private feelings. For this reason, people are often uncomfortable about the prospect of interacting with the patient and may therefore behave in ways that are detrimental to him or her.

Feelings and Attitudes

For a variety of reasons, others' feelings about cancer patients are likely to be negative. Some of these feelings are specific to cancer; others may occur whenever individuals are exposed to victims of undesirable life events. In analyzing these feelings and attitudes, we draw both from research in the cancer area and from theory and research in social psychology.

Cancer appears to be somewhat unique in its ability to arouse fear and feelings of vulnerability. For example, medical students and residents have been found to hold significantly more negative attitudes toward cancer than toward heart disease (Kaye, Appel, & Joseph, 1980). In health surveys the general public has expressed considerable fear of developing cancer and has many misconceptions about the chances of contracting and dying from the disease (Knopf, 1976; "Public Attitudes toward Cancer," 1980). For example, individuals markedly underestimate the incidence of cancer in the population. People believe that only one out of seven persons will develop cancer, whereas medical statistics indicate that the true incidence is one out of four. However, the public is unduly pessimistic about cancer mortality rates. People believe that only one in five cancer patients survives, yet medical statistics suggest that the survival rate (i.e., living 5 plus years from diagnosis) is about one in three ("Public Attitudes toward Cancer," 1980).

The disease also seems to evoke physical aversion and disgust in others, particularly when it is associated with mutilating surgery or physical deterioration. These feelings may be increased when one encounters striking and visible changes in a previously healthy person. Even family members report being taken aback by changes in the appearance of the patient. Aversion may also stem from individuals' fears that they will catch the disease. Indeed, patients in our support groups have described instances where they have been the only one at a party to receive paper eating utensils, or where they have been asked not to use public rest rooms or swimming pools (see, e.g., Kelly, 1975; "Cancer, More than a Disease," 1977). In one case a neighbor would not allow her child to play with a boy who had cancer (Cooper, 1980). In another, a woman's husband forbade her to touch her two young children for 2 years after she was diagnosed with cancer because he was fearful that the entire family would contract cancer

(Vachon & Lyall, 1976). The fact that the causes of cancer are not fully understood has contributed to this belief. Indeed, Kleiman *et al.* (1977) suggest that this myth about contagion is pervasive even among health care providers and is a major cause of avoidance and rejection of the patient.

In addition to fear, dread, and aversion, cancer in another person is likely to arouse feelings of anger, sadness, and depression on their behalf. Sympathy and concern for the patient are also common. The closer the relationship between a patient and another person, and the more dismal the prognosis, the more intense these empathic and sympathetic reactions may be.

Still other motives may lead individuals to derogate and blame cancer patients. In principle, these points apply in any situation where contact with someone who is suffering occurs. Lerner and his associates (1970, 1971; Lerner, Miller, & Holmes, 1976) argue that individuals are motivated to believe in a "just world" in which people "get what they deserve and deserve what they get." If we can believe that people do not suffer unless something is wrong with them or their behavior, we will feel protected from undeserved suffering ourselves (Lerner, 1970, 1971; Lerner & Simmons, 1966; Simons & Piliavin, 1972; Walster, 1966). Since having cancer is regarded as an extremely undesirable fate, individuals may be strongly motivated to protect themselves by attributing the disease to others' undesirable personal characteristics or their past behavior. Such reactions toward cancer patients are probably most prevalent among strangers and acquaintances.

Another factor that may contribute to a person's motivation to derogate an individual who is suffering is that such an attitude more or less absolves the derogator from any guilt for not helping the suffering person. As many health care providers can attest, dealing with a cancer patient who is depressed, fearful, and in pain can be a very stressful experience. Those in close proximity to the patient may become frustrated if they notice little improvement in the patient's morale after providing reassurance and help. Attributing the patient's negative feelings and fears to his or her own inadequacy in coping with the disease can relieve the sense of personal responsibility for being unable, or even unwilling to help. Derogation of this type may be especially likely to come from family members and health care professionals, who have frequent and continuing contact with the patient (Kalish, 1977, for descriptive corroboration of this point).

In addition to these motivational factors, there may be cognitive biases that lead observers to derogate and blame cancer patients. One such bias has been identified by Jones and Nisbett (1971) in their influential paper on actor-observer differences in the attribution process. Jones and Nisbett (1971) have argued that actors tend to attribute the causes of their behavior to aspects of the situation, whereas observers attribute the actor's behavior

to stable dispositions or personality characteristics of the actor. For example, an observer may reason that the cancer patient is complaining because he or she is "weakwilled, selfish and cowardly," while the patient attributes his or her complaints to the difficult or stressful circumstances. Theoretically, this difference occurs because the actor has more information than does the observer about the situational factors that are impinging on him or her. In contrast, the observer focuses on the behavior itself.

Since cancer patients are confronted with a genuinely stressful and aversive experience, many of the behaviors they manifest are likely to be negative (e.g., fear, depression; see Harker, 1972). Thus, observer biases toward dispositional attributions will often lead to negative inferences about the patient. This bias may be especially prevalent among family members and health care professionals who are more likely to witness unbecoming behaviors than are casual acquaintances or friends. Over time, this attributional tendency may result in the accumulation of tensions between the patient and others that are difficult to correct or counteract.

Several different kinds of negative feelings toward a person with cancer may be experienced simultaneously or in succession. The spouse of a colostomate, for example, may feel physical aversion regarding the condition, sadness that the spouse is suffering, and anger and resentment that he or she must spend so much time caring for the patient (Dyk & Sutherland, 1956; Sutherland *et al.*, 1952). In describing these negative feelings, we do not mean to paint others as intentionally cruel, unsympathetic, or unfeeling toward cancer patients. We do believe, however, that certain affective, motivational, and cognitive factors may unwittingly create negative reactions among them. These may occur even among individuals who have strong feelings of love, concern, and sympathy for the person with cancer.

Beliefs about Appropriate Behavior

Although most people have not had extensive experience in interacting with cancer patients, they often hold prior assumptions about how they should behave when with them. Some of these notions come from the acceptance of social norms and dictates for behavior toward the sick or dying. Others come from their conceptions about what types of comments and interactions are likely to be most helpful to the patient. Regarding the former, people are socialized to show concern for others who are seriously ill, and they learn ritualized behaviors of politeness such as visiting, calling, or sending cards. Consequently, they may feel strong obligations to behave in these ways toward a cancer patient. For example, if one's coworkers go to visit a fellow worker who is hospitalized with cancer, one may feel obligated to do the same.

Regarding their conceptions about what is beneficial for the patient, many people seem to feel that it is desirable for the patient to remain as cheerful as possible. It is often considered inappropriate for cancer patients to discuss problems they are having in coping with their illness, or to focus on a negative prognosis. These discussions are thought to be depressing to the patient, to encourage self-pity, or to undermine the patient's motivation to keep fighting the disease. The assumptions that patients should avoid thinking or talking about negative aspects of their situation and try to be as cheerful and optimistic as possible appear to be quite prevalent. According to Kastenbaum and Aisenberg (1972), a majority of nurses and attendants on a geriatric ward reported changing the subject when patients tried to discuss their feelings about death. The most frequent reason they gave for doing this was that they wanted to "cheer up" the patient, and they felt that the best way to do so was to focus the patient's attention on something else (see also Quint, 1965). Similarly, Harker (1972) and Garfield (1977) have suggested that most people believe open discussion of a cancer patient's difficulties would upset the person's emotional equilibrium. Kalish (1977) has argued that family members believe discussions about the disease and death will make the patient uncomfortable. Research also suggests that victims of other undesirable life events who discuss their problems are seen as coping poorly. For example, Coates, Wortman, and Abbey (1979) found that rape victims who made a brief negative comment about the incident 6 months after its occurrence were rated as less attractive and were regarded as more maladjusted than those victims who did not.

In fact, there are sound reasons to question the assumption that expression of negative affect is always maladaptive for the person with cancer. As discussed previously, many cancer patients are highly motivated to share their feelings rather than to conceal them so that they can clarify what is happening. Moreover, there is at least some evidence, indicated earlier, to suggest that the opportunity to express one's feelings is beneficial (Binger *et al.*, 1969; Cobliner, 1977; Cohen *et al.*, 1977; Derogatis *et al.*, 1979; Kaplan *et al.*, 1976; Kellerman *et al.*, 1980; Spinetta *et al.*, 1981; Spinetta & Maloney, 1978; Vachon *et al.*, 1977; see also Silver & Wortman, 1980, for a review). For example, children whose families maintained an open level of communication during the course of the illness demonstrated higher levels of self-esteem and reported feeling closer to their families members than did children whose families did not maintain open communication (Spinetta, *et al.*, 1981).

Although there are few studies in which the opportunity for ventilation has been experimentally manipulated, one experiment with widows has provided impressive support for the importance of ventilation. Raphael (1977) randomly assigned widows at risk for postbereavement morbidity to a treatment involving "support for the expression of grieving affects such as sadness, anger, anxiety, hopelessness, helplessness and despair [p. 1451]"

or to a no-treatment control group. This treatment occurred for a maximum of 3 months and included an average of just four sessions. However, when assessed 13 months after their spouses' deaths, women in the intervention group reported significantly better psychological and physical health than those randomly assigned to the no-treatment control group.

Conflicts about How to Behave

As elaborated earlier, people harbor negative feelings about cancer and cancer patients but believe these feelings should not be expressed to the patient. Instead, they assume that they must act cheerful and encouraging in their dealings with a person who has cancer. This state of affairs interferes with the frequency and quality of time that others spend with cancer patients. The prospect of coming into contact with someone who is seriously ill is likely to produce a great deal of ambivalence and conflict: Should one obey his or her desire to deny or avoid the unpleasantness associated with the cancer patient? Or should one try to hide his or her negative feelings and attempt to reach out to the patient, to be positive and cheerful? These discrepant feelings may be immobilizing, and patients may interpret such conflict and indecisiveness as active avoidance of them. Some people may resolve this ambivalence by voluntarily deciding to contact the patient. Still others may be required to spend time with the patient (as is generally the case with family and medical personnel) or may "force themselves" to visit because they believe it is the right thing to do.

In all of these cases, the interaction is likely to evoke a certain amount of anxiety for nonpatients. Evidence consistent with this was found in a study by Krant and Johnston (1977-1978) in which 55% of the family members of terminal cancer patients reported feeling uncomfortable or ambivalent about visiting the patient. The reasons stated included being upset by the patient's pain, feeling helpless, not knowing what to talk about, and fear of being near cancer. The prospect of contact with the patient forces people to confront their negative feelings; indeed, it often heightens these feelings since the patient's suffering and deterioration are usually more evident in face-to-face interaction. At the same time, people assume that every effort must be made to control their feelings and conceal their anxiety and distress. Parkes (1972b) has noted that family members worry constantly that they will "break down" and "betray their feelings" to the patient. Direct exposure to another who is suffering, coupled with an ever-present concern that one will reveal his or her feelings, or "say the wrong thing," makes many encounters with the patient awkward, uncomfortable, and tense. Furthermore, many people have had few encounters with others who are seriously ill and thus have little experience to guide them in this difficult situation.

Behaviors of Others toward the Person with Cancer

These reactions of others often lead to behaving in ways that are unintentionally damaging to the person with cancer. There is considerable evidence that people avoid cancer patients, that they discourage open communication with the patient, and that they give off conflicting behavioral cues when in the patient's presence. Each of these is discussed below.

Physical Avoidance

According to several investigators, health care professionals often avoid cancer patients or express strong desires to do so (see Schulz, 1978, for a review). For example, Pinkerton and McAleer (1976) report data that suggest that counselors are likely to provide less counseling to cancer patients than to patients with other equally serious disease-related disabilities. Physical avoidance is probably most likely to occur when a cancer patient's condition is deteriorating. The results of one study revealed that nurses took longer to answer the calls of dying patients than those of other individuals who were hospitalized (LeShan, 1964, reported by Kastenbaum & Aisenberg, 1972). Similarly, Artiss and Levine (1973) reported that doctors were uneasy about encounters with dying patients and often dreaded and avoided them. In another report, 77% of interns and 48% of residents surveyed perceived that physicians in their hospitals withdrew from terminal cancer patients (Fosson, 1980). Investigations have also reported some avoidance of cancer patients by friends (Greenleigh & Associates, 1979; O'Malley *et al.*, 1979; Silberfarb *et al.*, 1980).

A cancer patient at any stage of the illness may also experience avoidance and reduced physical contact with his or her family. For example, Dyk and Sutherland (1956) found low levels of physical assistance from spouses of colostomates even though, in most cases, the patients desired more help from their spouses than they were receiving. A survey of 142 family members of cancer patients in California found that 18% reported physical contact with the patient had become "cooled or withdrawn" since the illness (Greenleigh & Associates, 1979). Many other studies report a reduction or change in sexual activity as a consequence of the disease (Jamison, *et al.*, 1978; Meyerowitz, *et al.*, 1979; Morris, *et al.*, 1977; Silberfarb, *et al.*, 1980). Ironically, this change may be occurring at a time when cancer patients especially need physical contact as a sign of reassurance (cf. Lieber *et al.*, 1976).

Avoidance of Open Communication about the Disease

A number of empirical studies suggest that open communication with cancer patients is infrequent (Jamison *et al.*, 1978; Krant & Johnston, 1978; Sanders & Kardinal, 1977; Vachon *et al.*, 1977). For example, Jamison

et al., (1978) found that 89% of the mastectomees in their sample reported having had little or no discussion with spouse or significant other prior to surgery, 87% reported little or no discussion while hospitalized, and 50% reported little or no discussion after returning home. Similarly, a study of families of terminal cancer patients by Krant and Johnson (1978) found that discussions with the patient about dying were rare. Sixty-nine percent of the family members in the sample indicated that they had thought about the possibility of the patient dying, but of these, a large majority (78%) indicated that this topic had not been discussed with the person. Furthermore, when asked if issues such as life insurance, a will, or intentions for belongings had been discussed, 76% of the sample stated no. The results of this study also suggest that there are discrepancies between patients' and family members' perceptions of the others' perspective. For example, only 46% of the patients felt that their families knew they had a malignancy whereas 87% of the family members reported that they did. Even more dramatic, only 26% of the family members gave an affirmative answer when asked whether the patient was getting better, yet 46% thought that the patient *believed* he or she was getting better (Krant & Johnson, 1978).

It is not clear from these investigations whether the lack of open communication is brought about by others or by the patient. However, other studies (some of which were cited earlier) suggest that it is common for family members, friends, and medical staff to react unfavorably to open communication and that patients see this as a problem (Bard, 1952; Gordon *et al.*, 1977; Kastenbaum & Aisenberg, 1972; Mitchell & Glicksman, 1977; Pearlman, Stotsky, & Dominick, 1969). For example, Vachon (1979a) has found that breast cancer patients feel that others will react negatively if they display any emotional distress once the treatment has been completed. Dyk and Sutherland (1956) quote one cancer patient who felt that his family members "would never have the patience to listen to the whole story of my illness. . . . Their desire was always to hear from me that I was all right [p. 74]."

Family, friends, and medical personnel not only refrain from initiating discussions of patients' feelings but they may also try to influence patients to *conceal their feelings* (Dyk & Sutherland, 1956; Quint, 1965; Vachon, 1979a). For example, Quint (1965) interviewed 21 mastectomy patients at five intervals postsurgery and collected observations on patient-staff interactions. She found that physicians and nurses made it difficult for patients to express concern or ask questions by directing the conversation into "safe channels." Both patients and nurses reported that nurses did not permit open communication. Patients also reported that family and friends blocked them from discussing their illness. Barriers to verbal communication were greater the more extensive the cancer was. Other evidence suggests that family members are as likely as medical care givers to attempt to control the level of discussion with the patient (e.g., Bard, 1952; Binger *et al.*, 1969; Dyk & Sutherland, 1956; Glaser & Strauss, 1965; Klein, 1971;

Quint, 1965). Studies with other populations of victimized individuals provide further documentation that blocking them from ventilating their feelings is common (cf. Andreason & Norris, 1972; Glick, Weiss, & Parkes, 1974; Helmuth & Steinetz, 1978; Maddison & Walker, 1967; see also Silver & Wortman, 1980, for a review).

There are a number of reasons stemming from the feelings and beliefs of others, discussed earlier, why those in the cancer patient's social network may discourage expression of feelings. Open communication may be avoided because it is not consistent with most people's beliefs regarding what is good for the patient (Garfield, 1977; Kalish, 1977; Kastenbaum & Aisenberg, 1972). In addition, individuals may wish to avoid listening to the patient's feelings simply because they are unpleasant (Buehler, 1975; Kastenbaum & Aisenberg, 1972). Open discussion may even serve to intensify negative feelings that are already present. Thus, if a family member is upset about a patient who is dying, it may add to his or her distress to learn that the patient is afraid to die. Finally, others may wish to avoid listening to the patient's difficulties because it is even more difficult to control one's own feelings in these situations (Parkes, 1972b).

In addition to those mentioned, there are also some obvious and more altruistic motives for physical avoidance and for the avoidance of open communication. Friends may be fearful of intruding on the family's privacy by visiting the patient, and on the patient's privacy by bringing up sensitive aspects of the disease. During particularly difficult phases, friends or family may wonder if the patient wants attention, or whether he or she prefers to be left alone. Even family members may be afraid of harming, angering, or offending the person by mentioning certain touchy issues such as the costs of medical care or the possibility of death. Thus, genuine ambivalence about what to do, and real dilemmas over what the patient wants and needs may contribute to these tendencies of others to physically or emotionally withdraw.

Discrepancies in Behavior

Because of the underlying conflict between one's negative feelings about the cancer patient and one's beliefs about how to respond to him or her, individuals are likely to behave in contradictory ways when they do interact with a cancer patient. Especially likely are discrepancies between verbal and nonverbal behaviors directed toward the patient. When with the cancer patient, individuals may make a gallant effort to appear agreeable, optimistic, and cheerful. Yet, despite the fact that most people can voluntarily make optimistic statements, the nonverbal behaviors that accompany these statements may be more difficult to control. And, since nonverbal behavior is often a clue to one's true feelings (see, e.g., Argyle, 1975), the negative affect underlying interactions with cancer patients may well be manifested in their nonverbal behavior.

To our knowledge, no one has systematically investigated the nonverbal behaviors that occur when well persons interact with cancer patients. However, experiments dealing with confrontations between ablebodied and handicapped individuals seem directly relevant. These studies have shown that the ablebodied often express their discomfort in such situations by more rigid and controlled motor activity, fewer smiles, greater interpersonal distance, and earlier exits than they demonstrate when interacting with other ablebodied individuals (see, e.g., Farina, Holland, & Ring, 1966; Kleck, 1969; Kleck, Buch, Goller, London, Pfeifer, & Vukcevic, 1968; Kleck, Ono, & Hastorf, 1966). If these results are generalizable to persons with other kinds of stigmata, there may be a considerable discrepancy between others' verbal statements and their nonverbal behaviors toward cancer patients. For example, an individual may offer reassurance while maintaining an awkward interpersonal distance or while talking in a sad or nervous voice.

There is evidence that patients are aware of negative nonverbal behaviors and find them disturbing. For example, in an interview study of 50 patients hospitalized with chronic illnesses including cancer, Cobb (1956) found that patients easily picked up signals of nurses' attitudes from their tone and manner and wished nurses would transmit more concern and compassion nonverbally. Perhaps for this reason, the importance of nonverbal communication modes in medical settings is being increasingly stressed (see, e.g., Bennett, 1977; DiMatteo, 1979; Friedman, 1979a; Parkes, 1972b; Verwoerd, 1966).

The conflict between individuals' negative feelings and their desire to respond positively to the patient may also be evident in discrepancies between verbal behaviors in a given context. For example, a person may be supportive to a cancer patient one moment and rejecting the next. One of the women in the authors' support group reported that her daughter once said to her, "Does your arm hurt, Mother? Well, don't tell me if it does." Discrepancies may also occur between behaviors in different situations and at different times. For example, a friend who has lavished attention on a cancer patient after the initial diagnosis may subsequently not visit or call at all when the prognosis worsens. There may also be discrepancies between a person's expressed intentions and his or her subsequent behaviors. People may promise to call or visit but then fail to fulfill these promises, perhaps because of their underlying ambivalent or negative feelings.

Discrepancies in behavior may be especially likely to come from family members, since it is the family members who generally have the most sustained contact with the patient (Aitken-Swan, 1959; Binger *et al.*, 1969; Dyk & Sutherland, 1956; Klein, Dean, & Bogdonoff, 1967). 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. They frequently become emotionally drained from trying to keep pace with rapid fluctuations in physical condi-

tion, mood, and reactions of the patient. Frustration results from efforts to help the patient that have little impact on the course of a progressive disease. Physical exhaustion is common among close care givers, and the strain of financial difficulties often accompanies it. Family members' own needs, interests, and problems are neglected as they struggle to stay on top of a complicated and demanding situation.

Because of all the pressures upon them, even the most patient and understanding family members are likely to direct occasional negative outbursts toward the patient. As the stress of interacting and caring for a suffering and ill person continues with no improvement in sight, these outbursts may become more frequent. Yet, they conflict with the family member's feelings about how the patient should be treated, and thus, they are likely to be followed by strong feelings of guilt and remorse and by displays of love and concern for the patient. It may add to the patient's frustration and confusion to be treated harshly one moment and lavished with kindness the next.

Impact of Other's Behavior on the Person with Cancer

In summary, when a person learns he or she has cancer, that knowledge produces a need for clarification and social support. As the disease progresses and the patient attempts to cope with all of the events ensuing from the illness and its treatment, the need for satisfying social interaction becomes more intense. But most cancer patients find themselves in a situation where their needs for information and social support are thwarted.

The changes in their social relationships are likely to be profound. Casual friends and acquaintances may begin to avoid the patient completely. When people do visit, any attempts to provide reassurance and support are unlikely to be convincing. Despite others' best intentions, their interactions with the patient are often characterized by awkwardness, hesitancy, uncertainty, and tension. Many of those who interact with the patient may attempt to keep the conversation superficial and thus, avoid the topics that are really on the patient's mind. While this evasion may often be motivated by a concern for the patient's welfare, the patient may infer that others are not really interested in his or her feelings. Friends, family members, and health care professionals are likely to voice reassurance on the surface, but manifest negative nonverbal behaviors as well as inconsistencies in behavior over time. Moreover, their efforts to be reassuring and agreeable may often backfire into an oversolicitous and patronizing attitude toward the patient. Even from family members, patients may receive mixed messages and occasional negative outbursts as the stress of caring for an ill person takes its toll. Positive messages that are laced with subtle and sometimes overt negative signs can leave the patient feeling hurt, rejected,

and certainly confused. As this cycle continues, the patient's need for social validation and support may reach overwhelming proportions.

Since they elicit signs of rejection from virtually everyone, and since the negative messages are fairly consistent across situations and over time, patients may draw the conclusion that they are worthless and unlovable. The impact of consistently negative or ambiguous feedback on the patient's self-esteem can be devastating (Dyk & Sutherland, 1956). Over time, patients may come to internalize the views they perceive others to hold (Kleiman *et al.*, 1977). What Goffman (1963) has stated about the stigmatized in general may hold for the cancer patient: he or she may incorporate the views of others into his or her identity and begin to feel shame and guilt, self-blame, self-derogation, and self-hatred. Mastrovito (1972), for example, has speculated that more than half of the cancer patients treated in his clinic over the past 3 years expressed self-revulsion and negative self-concepts. Ultimately, the self-doubt and isolation that result from disruption of one's social relationships can contribute greatly to the cancer patient's distress.

Attempts by the Person with Cancer to Solve the Interpersonal Dilemma

Because the disease and its associated problems may leave the patient physically and emotionally drained, most patients do not have a great deal of energy to divert to improving their social relationships. Yet, as the need for information, clarification, and support becomes more desperate, the individual with cancer may try any of several strategies to break out of the crippling interactional patterns that we have been describing. For example, he or she may exaggerate the negative aspects of the situation so that others will respond. However, the more a patient dwells on his or her problems, the more alienated and rejecting others are likely to become (Lerner, 1970, 1971).

At some point, it may occur to the patient that attaining useful information about one's own responses is probably incompatible with getting acceptance and approval from others. Although the best way to validate one's feelings may be to discuss them with others, the best way to get support may be to indicate that everything is fine and that one is coping well. Thus, the patient may try to stave off the rejection and avoidance of friends by adopting a more positive self-presentational strategy. Hackett and Weisman (1969), in a paper on reactions to imminent death, argue that the patient "learns that to pursue his doubts by asking questions seldom yields more than uneasiness between himself and those upon whom he depends for companionship. Therefore he stops asking and becomes a player in the deathbed drama in which optimism is the theme [p. 304]." And from the cancer

patient's point of view, Rollin (1976) recalls, "I got many congratulations for being so brave and cheerful. I liked that, so I got more brave and cheerful. And the more brave and cheerful I was, the more everyone seemed to love me, so I kept it up. I became positively euphoric [p. 70]."

There are two problems with this approach to the patient's dilemma. First, this may stop avoidance responses from some people (e.g., those who cannot deal with the patient's pain and suffering), but not from others (e.g., those who fear the illness is contagious). Second, since the patient is aware that he or she is using false pretenses to gain approval from others, any support received may provide little information to the patient about his or her true worth (Jones & Wortman, 1973). Positive feedback may have little impact on the patient, since it is likely to be attributed to the patient's obvious need for it or the self-presentational strategy employed to obtain it. In fact, a general problem for the patient who wishes to correct their communication problems is that there is often little contingency at all between his or her behavior and the responses of others. Ambiguous and negative feedback from others stems as much from their own anxiety or distress as from the patient's actual behavior. Thus, the patient's attempts to alter the situation may be met with a seemingly random pattern of responses. As a consequence, the patient may learn over time to expect negative or ambiguous messages from others.

So most cancer patients find themselves in an uncomfortable situation, a "Catch-22": Either they can express their feelings and be themselves, thereby incurring others' avoidance and rejection, or they can enact a charade, pretending that everything is fine, and obtain at least some support from others. Because neither of these alternatives is satisfactory, the patient may vacillate between them, sometimes putting on a good face, and sometimes confronting others with his or her pain and anxiety. This vacillation, of course, pollutes the social environment still further and makes it even more difficult for friends and relatives to know how to respond. Most patients are not in a position to test the hypothesis that *all* cancer patients are treated in this manner by friends and loved ones, so they stay trapped within this dilemma indefinitely. If it continues unchecked long enough, this process may lead to complete withdrawal from the social environment and to severe and chronic depression.

IMPLICATIONS FOR TREATMENT INTERVENTIONS AND FOR SUBSEQUENT RESEARCH

Many authors have talked about the social isolation of the cancer patient (e.g., Forester, *et al.*, 1978; Giacuinta, 1977; Klagsbrun, 1971; Lewis & Bloom, 1978-1979). In principle, this process of social isolation may be stopped or reversed at any point by natural circumstances or by therapeutic

intervention. Some patients may not experience this social breakdown as acutely as others because of exceptionally sensitive relatives or friends with whom they can openly communicate without rejection or avoidance. Occasionally patients' cancers may be effectively treated before interpersonal networks are disrupted. Yet for many cancer patients, especially those who are debilitated by their illness for a long period of time, none of these naturally occurring preventions may apply. These patients may benefit from psychological interventions that prevent or correct problems in their social relations and from health care providers' awareness and understanding of these problems. The following sections discuss the implications of what has been presented here for intervention with patients and their family members and offer some preliminary guidelines for the health care professional and for the general public.

Potential Treatment Interventions for Patients and Family Members

Family Counseling

One treatment suggested by our analysis is a family counseling program that makes cancer patients and their families aware of the complicated social environment in which they may be trapped and that encourages more open communication (Binger *et al.*, 1969; Cohen, Goldenberg, & Goldenberg, 1977; Krant *et al.*, 1976; Olsen, 1979; Sheldon, Ryser, & Krant, 1979; Vachon *et al.*, 1979; Wellisch *et al.*, 1978). It appears that families in which members communicate freely with one another are more likely to adjust to cancer effectively (Cohen *et al.*, 1977). Family counseling could increase the frequency and effectiveness of communication within families by providing training in communication skills and regular occasions in which to use them. In addition, exposure to other families could provide clarification of the problems associated with the disease. For example, family members could learn that their feelings of anger and guilt are normal under the circumstances.

In an article on a therapy program for couples in which the woman has had a mastectomy, Witkin (1975) describes a misunderstanding that is extremely common. Many husbands assume that they should not have sex or indicate a desire for sex until their wife suggests it:

"One husband stated, 'I didn't have sex with my wife for a long time because I felt she really didn't want it, what with the operation and her breast gone. . . . I imagine I wouldn't feel like it after such an operation.' In his fear of early intercourse, the husband may be genuinely concerned about his wife and want to do what's best for her. What happens is the reverse: the woman interprets his abstinence as confirming her worst fears, that he is disgusted, sees her as half a

woman, can't stand looking at or caressing her, doesn't want her anymore [p. 300]."

Misunderstandings such as this can be headed off or cleared up through a family counseling program.

Peer Support Opportunities

A second implication is that it might be useful to increase cancer patients' access to others who have experienced cancer. This can be accomplished through support groups for cancer patients. Many types of groups exist in which cancer patients come into contact with other patients, but these groups vary in the emphasis they place on peer interaction. Self-help groups typically hold interaction among members as their primary goal (Adams, 1979; Cole, O'Connor & Bennett, 1979; Johnson, 1980; Parsell & Tagliarini, 1974; Peebler, 1975; Pellman, 1976), whereas other types of groups deemphasize this and have educational or psychotherapeutic goals instead (e.g. Ferlic, Goldman, & Kennedy, 1979). Still others include peer support as one of many goals (e.g., Foster & Mendel, 1979; Gustafson & Whitman, 1978).

There are many specific reasons why these groups can provide especially rich opportunities for clarification and support. First, they usually provide an ideal setting for open communication. Members are encouraged to share their problems and feelings in an atmosphere of understanding and support. Second, cancer patients can exchange factual information about such things as where to get a good price and fit on a prosthesis, how to minimize nausea from chemotherapy, how to go about making a will, and how to apply for disability benefits. Group members can also obtain advice and suggestions from one another about how to cope with specific personal problems. In trying to make decisions about such issues as what to tell people at work or how much to tell one's children, patients can profit enormously from learning about the experiences of others who have dealt with these problems. Third, interacting with similar others should help the patient make a more accurate attribution about the things happening to him or her. For example, by talking with other cancer patients, it may become evident that rejection or avoidance by others is a normal consequence of the disease, not a reflection of personal inadequacy and weakness. Finally, these groups offer an array of others from which an appropriate comparison person can be selected. In other words, it is possible to find another person with whom to compare experiences who is similar on such dimensions as age and type of cancer.

The few attempts that have been made to evaluate the effectiveness of groups for cancer patients suggest that they are beneficial (e.g., Bloom, *et al.*, 1978; Ferlic, *et al.*, 1979). Unfortunately, studies have not evaluated the

peer interaction aspect of these groups as distinct from other aspects (e.g., dissemination of information). In fact, we are aware of no firm evidence that interaction with similar others is beneficial to people coping with major life events. Despite the popularity of self-help groups in recent years for people with a wide variety of life problems (Lieberman & Borman, 1979), and the many reasons mentioned above why they may be helpful, they may also be stressful or even harmful to participants at times. Many specific questions and issues about peer interaction are worthy of attention.

For example, when are cancer patients and others coping with misfortune receptive to interacting with similar others, and when do they prefer to avoid such contact? (McIntosh, 1977; Mitchell & Glicksman, 1977; Parkes, 1979a). At the earliest stages of the disease, people may be unreceptive to interactions with "similar others" because of the difficulty in accepting a new identity as a cancer patient. Moreover, some people with cancer may be hesitant to interact with other cancer patients at any time. For some, discussing problems with others is seen as a sign of weakness. These factors must be recognized in working with cancer groups.

Another question concerns the effects of variations in the degree of similarity between patients. Does the value of interacting with others in similar circumstances differ depending on whether they are doing better or worse, either psychologically or physically? Sanders and Kardinal (1977) have indicated that cancer patients often use others who are doing well as a yardstick to measure their own progress, but conceivably this social comparison might be distressing if the patient does not "measure up" favorably. Direct contact with other patients may also make it difficult to employ certain psychological defenses. For example, a patient who is coping with fear of recurrence by denial, thus believing that he or she is cured, may be made very anxious by encountering a similar cancer patient who has had a recurrence. In addition, the attitude of the comparison person may be a critical determinant of the value of an encounter. A study by Carey (1974) has suggested that the opportunity to talk openly and honestly with another dying person facilitates effective coping only when the dying person faces death with peace and equanimity. Talking with a person who was unable to accept his or her approaching death was negatively associated with effective coping. Brickman and Bulman (1977) have discussed the advantages and disadvantages of social comparison in general, highlighting that many comparisons can be disconcerting.

A related issue arises when family members participate in patient support groups. Is it always desirable for family members and patients to share their feelings in the presence of the other? Often it may be an important avenue for clearing up misunderstandings and facilitating further open communication. Sometimes, however, a member of the group may feel unable to express his or her concerns in the presence of their loved one. This hesitancy can stem from fear that particular concerns would hurt, worry, or

upset the person. For family members these concerns might be intense personal grief, or personal problems stemming from the disease such as trouble at work. For the person with cancer, they might be new symptoms or fear of death. In our support group, we periodically divide into two smaller groups in such a way that the members of each particular family are not together. Then, these sensitive issues can more easily be brought up and the group participants can help decide whether they should be shared with the other person or not at that time. In these subgroups, the presence of both patients and family members is desirable (as opposed to dividing into one all-patient group and one all-family group) because their different perspectives can each be brought to bear on the discussion. For example, a family member who is worried about making plans for terminal nursing care may be advised by patients how this matter can be brought up with the person concerned. At the same time, other family members can indicate that these concerns are understandable and they are not something about which to feel guilty or embarrassed.

These and other major problems that may arise when cancer patients interact with other cancer patients have been discussed by Kleiman *et al.* (1977). Although we believe that contact with similar others is generally helpful, we feel this treatment should be utilized with care until further research has been conducted. Competent group facilitation can help to minimize the possibilities for problematic interactions. For example, we frequently need to remind members in our groups that their experiences, while generally helpful to others, are not necessarily applicable to everyone with cancer. Also, attendance at groups and participation in similar peer interaction programs should be strictly voluntary. Too often one hears of a newly diagnosed patient being visited by a volunteer who is a former cancer patient without having been advised or consulted beforehand; consequently, these visits are often perceived as distressing rather than helpful. Opportunities for peer interaction are highly desirable in our view, but they should be provided only with careful consideration of the individual patient's wishes and needs, and of the conditions under which the interaction will take place.

Hospice Care

In addition to family counseling and peer support groups, hospice environments can be a source of help for patients with advanced cancer. Hospices are typically places where dying patients can receive specialized physical and emotional care. Modeled after St. Christopher's Hospice in Sydenham, England, their goals usually include keeping the patient comfortable, free of pain, and alert if possible, and providing emotional support to patient and family. Hospice policies tend to encourage frequent and open interactions between patients and family members, between family

members and staff, and between family members and other families (Parkes, 1979a, 1979b). This characteristic is in sharp contrast to the conventions and practices of most traditional hospitals.

In addition to encouraging open communication, hospices are likely to generate interaction between patients. The advantages of such contact are optimized by the similarity among patients with respect to the stage of the disease. In fact, empirical studies in hospices can provide useful information on the benefits and risks of contact between cancer patients. For example, Parkes (1979a) found that hospice patients were generally not upset by the deaths of other patients. Furthermore, hospices have been found to be preferred by patients over other inpatient care environments and to be beneficial to both patients and families (Hinton, 1979; Parkes, 1979b).

In summary, the most promising treatment interventions for cancer patients in helping them to meet their needs are suggested to be family therapies, peer support groups, and hospice care.

Guidelines for the Health Care Professional

From the time of diagnosis on, the health care professional is in a unique position to intervene on the patient's behalf. Through an awareness of the patient's needs for validation and support and of the destructive pattern of feedback that the patient is likely to receive from those in his or her social environment, health care professionals can take specific actions to help prevent or correct interpersonal problems. At a minimum, they can avoid relating to the patient in ways that exacerbate these problems.

One step that the health care professional can take early in the patient's treatment is to make available some information about the sensations, feelings, and possible emotions that are likely to accompany the disease or treatments.³ As noted earlier, the literature has generally shown that information reduces the level of patient distress. Yet the available evidence suggests that such information is often not provided (cf. Messerli *et al.*, 1980; Mitchell & Glicksman, 1977; Morris *et al.*, 1977; Peck & Boland, 1977). For example, both Mitchell and Glicksman (1977) and Peck and Boland (1977) have conducted interview studies with approximately 50 cancer patients undergoing radiation therapy. In the study by Mitchell and Glicksman, the majority of patients indicated that they had received no information whatsoever from the referring physician about the nature of the therapy they were to receive. These results were corroborated by Peck and

³These recent publications by the National Cancer Institute (available free directly from the agency) may be very helpful to health care providers in providing information to patients, and in understanding the psychological aspects of the disease. *Coping with Cancer: A Resource for the Health Professional* N.I.H. Pub. No. 80-2080 September 1980, and *Coping with Cancer: Annotated Bibliography of Public, Patient, and Professional Information and Educational Materials*, N.I.H. Pub. No. 80-2129, May 1980.

Boland (1977), who concluded that patient beliefs regarding treatment were usually "inaccurate, pessimistic, and alarming [p. 181]."

Many physicians are reluctant to discuss the possibility of negative emotions or undesirable side effects with the patient even if the patient specifically requests this information. It is often believed that such discussions will increase the likelihood that the patient will experience the emotion or side effect in question. The interview study by Peck and Boland (1977), just mentioned, suggests that this is unlikely. Patients who had been informed about possible negative side effects of radiation appreciated this information and praised their physicians for providing it. None of the patients in the study complained because the physician had told him or her about a side effect that did not occur. However, patients who had not been warned about side effects that did occur were angry and disappointed with their physicians. Our experience in support groups has suggested that patients are often terrified by unexpected side effects and believe them to be evidence of metastasis. Interestingly, Peck and Boland (1977) also found that many patients assumed the worst about unexpected side effects and had difficulty accepting their physicians' explanations after the side effects had occurred.⁴

A second step that health care professionals can take at early stages of treatment is to inquire about the social support network that is currently available to the patient. Patients who lack social support may be in special need of time and attention from the health care staff. In cases where the patient's potential social support network is weak or underdeveloped, the health care providers may be able to play a role in mobilizing the support system (see Cobb & Erbe, 1978). For example, the likelihood that family members will provide support for the patient can be increased by involving them in the patient's care (Lewis & Bloom, 1978-1979). Family members who do not understand the nature of the disease or the medical procedures involved are not in a position to offer encouragement or support to the patient. A family member who is unaware of the side effects of chemotherapy, for example, may be annoyed rather than sympathetic with the patient's nausea and general tiredness.

Health care providers can also help by encouraging open communication, both in their own interactions with the patient and in the patient's interactions with family members. As noted earlier, available evidence suggests that the opportunity to discuss one's experience helps the patient reach an understanding of what is happening to him or her. Furthermore, misunderstandings and resentments can accumulate in settings where people are unable or unwilling to discuss their feelings about the disease (see,

⁴It is important to note that there is evidence for individual differences in the desire for information and its effects (Christopher & Pfeiffer, 1980; Rice, 1982; Visser, 1980). However, a thorough discussion of these issues is beyond the scope of this chapter.

e.g., Glaser & Strauss, 1965). For example, a mother in our support group who was suffering from terminal bone cancer began drawing away from her children because she wanted them to learn to take care of themselves so that they would be prepared for the time when she would be gone. However, the children, who were unaware of her motives, were hurt and confused by this apparent rejection of them. In situations such as this, help from the health care provider in discussing the feelings behind specific behaviors can alleviate some of the patients' and family members' distress.

A final implication of this model for health care professionals is that it may help to explain why they often have ambivalent feelings toward their patients—patients whom they are supposedly trying to help. Past research has suggested that even a single encounter with a victim can be a powerfully distressing experience and can result in blame and derogation of the victim (Coates *et al.*, 1979). In one study, nurses who worked on a new cancer care unit were found to have only slightly lower levels of stress, as measured on the Goldberg General Health Questionnaire, than new widows and considerably higher stress than breast cancer patients beginning radiation treatment (Vachon, Lyall, & Freeman, 1978). Since health care professionals frequently have repeated and intense interactions with people who are suffering, it is not surprising that ambivalent and negative feelings should develop.

Maslach (1976) has studied the phenomenon of burnout among professionals working in the helping fields. It is extremely common for such workers to come to think of their patients or clients in derogatory terms, and even come to believe that the clients deserve any problems they have. According to Maslach (1976), "They lose all concern, all emotional feeling, for the persons they work with and come to treat them in detached or even dehumanized ways [p. 16]." Many health care professionals believe that their negative reaction to their patients is a reflection of some personal failing (Maslach, 1976; Pines & Maslach, 1978). Research has suggested that burn-out rates are lower for professionals who can choose to minimize contact with patients or clients when the stress becomes too much for them and for professionals "who actively express, analyze, and share their personal feelings with their colleagues (Maslach, 1976, [p. 22])." (See also Vachon, 1978, 1979b; Vachon, Lyall & Freeman, 1979 concerning stress among those caring for the terminally ill and ways to alleviate it, and Edelwich & Brodsky, 1980; Freudenberger & Richelson, 1980; and Pines & Aronson, 1980 on burnout in general).

General Guidelines

When people have been alerted to the many things they are likely to do that disturb cancer patients, they usually wonder, "Then what *should* I do in order to be helpful?" A few implications for personal experiences with

cancer patients can be derived from our analysis. Since each person and situation are different, however, and since research lags behind theorizing in this area at present, these guidelines ought to be considered tentative.

First, our discussion emphasizes the importance of permitting patients to talk about their feelings, if and when they wish to do so. Because many patients have learned that things go better if they keep their concerns to themselves, it may be difficult to initiate meaningful conversations. Yet, one can attempt to create an atmosphere of understanding with the patient in which open discussion is possible. A first step in this direction is to convey that one is receptive to hearing about the patient's concerns. For example, a comment such as "it must be hard" might signal to the patient that negative feelings are acceptable.⁵ Pressuring the patient to "open up", however, would be inadvisable for at least two reasons. First, it is a counter-productive technique for fostering spontaneous and natural conversations. Such pressure is likely to lead to discomfort and superficiality rather than meaningful exchanges. Second, the need to express feelings is likely to vary considerably from patient to patient and over time for any given person. The most one can do, then, is to create opportunities for a cancer patient to ventilate while letting him or her determine when the time is right.

When a cancer patient is sharing his or her feelings, skillful and attentive listening is desirable. This entails attempting to understand but not evaluate or judge the person. It also involves restraining the typical impulse to react to every problem mentioned with a comment, piece of advice, or proposed solution. Common responses to the expression of others' woes are "I know how you feel," or "don't worry, it will be all right." These well-meant remarks are often unhelpful to cancer patients, we have found, because they minimize the person's problems and offer false reassurance. Merely to acknowledge that the person's concerns are being heard is probably a better response. In general, attentive listening constitutes a powerful and frequently overlooked means of support.

Another implication of the foregoing analysis is that one should try to be conscious of any cheerful or optimistic facades adopted in the patient's presence. Any attempts to cover up strong feelings of sadness, pessimism and anxiety are unlikely to be convincing; moreover, they can add to the patient's sense of confusion and bewilderment. In contrast, attempts to maintain a basically honest relationship with the person may be helpful. Such a relationship can serve as a source of strength at a time when others appear artificial. In addition to these reasons for questioning positive presentations, the difficulty of consistently acting upbeat if one feels low is a factor. This effort may take a considerable toll on family members and friends over time. We do not mean to imply that one should always admit or display negative feelings to the patient—only that continued efforts to cover them up are questionable in that they can be detrimental to everyone involved.

⁵This suggestion has been made by Elisabeth Kubler-Ross in numerous talks she has given.

A related suggestion is to realize that these negative feelings are common among family and friends of cancer patients. If they are intense and persistent, it may help to take steps to manage or relieve them. Some of them might be shared with the patient in a sensitive and caring manner. For example, it might help to express a sense of helplessness about not being able to do more for the person or to share the emotional pain felt in watching the person suffer, but only if this can be done without imputing any blame. These admissions could potentially make it easier for the patient to express his or her feelings.

In many cases, however, it might be inadvisable to share negative feelings with the patient. For example, it would probably serve little purpose to tell a patient that one resents or feels angry with him or her for being ill. A better way to handle these feelings would be to discuss them with someone else who is less likely to be hurt by them. Along these lines, it could help to take advantage of support groups that are available for friends and family of those with cancer. Through this outlet for personal feelings, one may gain an ability to interact with the patient more confidently, as a better listener, and in a more genuine manner. In fact, sometimes the most helpful thing one can do for the patient is to recognize that one's own emotional needs deserve attention.

Perhaps the best advice on how to act in the presence of someone with cancer is from a patient. These words were spoken by a remarkably insightful woman who lived for eight years with lung cancer, and who was an inspiring and constructive force in the self-help groups in which both she and the authors took part: "What can you say to someone who has cancer? . . . All you can say is what you really feel. You can't upset us by telling us you're frightened or don't know what to say. We'd rather hear that than listen to someone say 'You're going to be just fine.' How can anyone know that? My doctors don't. I don't. I'm much happier when someone says 'I'd like to be your friend,' or 'I feel bad you have this disease' or 'I really give you credit for putting up a good fight.'"⁶

- Cancer is undeniably prevalent; by statistical probabilities it will touch each of us in some way during our lifetimes. Very often, it will require difficult adjustment on the part of family and friends, and most of all, for the patient. This chapter is an attempt to examine the interpersonal dynamics of cancer. Both cancer patients' and others' perspectives have been consid-

⁶This quote is taken from *The Sky is Blue Now: Thoughts on Living and Cancer*, a copyrighted booklet based on the memoirs of Anita Siegel and distributed by the Self-Help Center, 1600 Dodge Avenue, Suite S122, Evanston, Illinois 60201 for \$1.00 to cover postage and handling. This is a useful source of information on the psychosocial effects of cancer. Also recommended is the N.C.I. publication *Taking Time: Support for People with Cancer and the People Who Care about Them*, N.I.H. Pub. No. 80-2059, September 1980.

cred, as well as the causal influences they exert on one another. Relevant research was presented when available, but since strong data do not currently exist on many issues raised, the reasoning in this paper is in need of further documentation. It is hoped that our endeavor to understand and articulate the social problems experienced by cancer patients, as well as their causes and consequences, will stimulate research and in some way help those affected by this disease.

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