

Social Support and Adjustment to Cancer

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Social support refers to the provision of useful information and advice, assistance with tasks, and emotional sustenance to another individual (1). Past research indicates that it is a powerful influence on physical and mental health and on general well-being, particularly in times of crisis or stress (2). In the case of the cancer patient, support from family, friends and medical staff appears to be helpful in emotional adjustment to the disease (3,4,5); furthermore, when the interpersonal relationships of a cancer patient are not supportive, he or she may have difficulty adjusting (6).

Ironically, misfortunes such as cancer frequently lead to problems in social relationships rather than an outpouring of support (7). These problems stem from many complicated causes, but, summed up briefly, they are the result of reactions to the crisis by both the patient and their loved ones. For example, in coming to terms with the disease and in going on with life, cancer patients greatly need clarification of their feelings and support (8). At the same time, others often feel threatened, apprehensive, and uncomfortable about the person's disease, and may therefore be unable to provide effective support (9). As the process of adjusting continues, communication problems, misunderstandings, and conflict can mount, leading to a very troubled interpersonal situation. Thus, cancer may impair one of the best resources a person has available for coping with the disease—the support system (6,8).

In 1976, the first two authors made these observations while facilitating self-help and emotional support groups for cancer patients and their families in the Chicago area. A review of the psychosocial literature on cancer suggested that our observations were accurate, although at the time the evidence was scarce and relatively weak. Subsequently, we developed a more thorough review and analysis on these issues, which described the complex impact of the disease on patients and their social relationships (6,8).

In 1978, we planned an exploratory investigation of social support and cancer, the results of which are reported here. The study, which took three years to complete, was supported by funds from the Biomedical Research Committee at Northwestern University and the Illinois Comprehensive Cancer Council.

We chose as our study population patients with breast and colo-rectal malignancies because of the high incidence of these tumors in the general population. The Northwestern Memorial Hospital Tumor Registry identified patients with primary cancers in these sites who had been diagnosed between June of 1979 and July of 1980. Sixty-six percent of the 120 patients whom we approached agreed to be interviewed (68 patients) or to complete a comparable mail questionnaire (11 patients). Three-quarters of these patients had been diagnosed with breast cancers, and the remainder with colo-rectal malignancies. Time since diagnosis at the time of interview ranged from 6 to 20 months. Fifty percent had stage I cancers, 10 percent were stage II, 34 percent were stage III, and 6 percent were stage IV. The interview items concerned interpersonal problems, social support, and physical and psychological adjustment.

One issue addressed in the study concerned patients' perceptions of the most helpful and unhelpful things done by others since diagnosis. Our results point to the importance of skillfully communicated information and advice in medical care, and to the positive value of emotional support for cancer patients from everyone in the social network, family, friends, and medical staff alike. Physicians were mentioned as frequently as family as sources of the greatest help. Two kinds of support for cancer patients from physicians were mentioned. One involved providing information and advice. For example, one subject's answer to who and what had been most helpful was: "Dr. X who operated on me . . . spelled it right out for me, as the saying goes. He told me it might not be malignant, or it might be, and he told me the different types of treatment I might need to have . . . And he

told me not in medical terms, but in lay terms you could understand." Interestingly, subjects mentioned as helpful not only physicians' advice on the medical aspects of the disease, but also advice on psychosocial issues. For example, "(The doctor) told me what to expect physically, and much more important, told me what to expect emotionally, and told me how to try to handle it." In contrast to reports on the helpfulness of advice from physicians, patients felt that advice provided by relatives and friends was generally unhelpful. Patients also felt it was unhelpful when physicians provided too little information, yet there was no mention of physicians who provided too much information.

The second type of support from physicians, seen by patients as particularly helpful, was emotional support. Patients referred to their doctors' concern, and also to their understanding and reassurance as particularly helpful. One said of the doctor, "He always has time to listen even though he has a lot of patients." Another said the most helpful person was "the doctor who let me cry, [who] permitted me to talk." In total, more than 90 percent of the people in our sample mentioned that providing some form of emotional support was one of the two or three most helpful things anyone had done. Moreover, many of the reports of most unhelpful actions involved an absence of emotional support from those who provided medical care. Specific instances included mention of a physician or other health care provider who had been cold or too clinical in manner, seemingly unfeeling or insensitive to a patient's feelings or emotional state, and too abrupt. It was clear that patients look to the medical staff for compassion and sensitivity as well as for technically competent treatment.

In addition to these results on the most helpful and unhelpful incidents, our study provided further evidence that cancer patients who have social support from family and friends are better able to cope with the disease than those who don't. Among patients with a more favorable prognosis, those with stage I and II cancers, amount of support was associated with significantly less depression and anxiety, and significantly higher self-esteem and satisfaction with life. Among patients with a poorer prognosis the results were less clear, but the data suggest that these patients' physical problems elicited significantly more attention and support which, in turn, positively influenced their adjustment to the disease. There was also evidence that support reduced the deleterious effects of stress of cancer on health and well-being.

Our study also attempted to determine if cancer patients received enough support, or if there was evidence of problems in their interpersonal relationships. For most of the sample, support from family and friends appeared to be adequate. However, for a stable minority—approximately one-quarter of the sample—significant interpersonal problems or changes were associated with disease. Twenty-six percent reported that having cancer had changed their relationships with family members, and 16 percent of the sample were rated by interviewers as having weak or very weak support. In 18 percent of the cases, there was evidence of negative reactions in at least one family member, usually characterized by lack of support. Typically, those patients who showed evidence of problems in social relationships or support were patients with more advanced disease and poorer physical condition. Yet patients with advanced disease were less likely to participate in our study than patients with controlled disease, so the rates of interpersonal problems found in this study are probably underestimates of the rate for cancer patients overall. Patients with advanced disease in particular are likely to have a much higher incidence of interpersonal difficulties than the incidence estimates of this study.

This problem highlights the need for institutional cooperation in studies such as this. Many of the patients who did not participate in our research were not approached to take part because their physicians withheld permission. Consequently, the sample was less representative than it might have been. To select a representative sample, every patient who is eligible for a protocol must be approached personally and given the opportunity to decline. Ideally, physicians should encourage patients to participate in research studies such as this, and should never discourage a patient who wishes to participate in such a study.

The reason why a few of the surgeons did not cooperate fully with this study was that they felt that the interviews would be too upsetting or stressful for some



patients. Because this was such an important issue, we decided to evaluate the effects of our interview in two ways. First, immediately after each interview the interviewer made a systematic assessment of how the interview seemed to have affected the patient. Second, four to six months after each interview we sent the subject a follow-up questionnaire; 81 percent of these questionnaires were returned. Summarizing the information from these two sources, the interview seems to have been a neutral or positive experience for a sizable majority of the patients. The few subjects who felt uncomfortable about the interview showed no signs of major psychological disturbance or extreme emotional distress as a result of the interview. In fact, many felt it had been helpful to be involved. The following quotes are representative: "I integrated the past year's happenings somewhat as a result of the interview." "It was cathartic. It gave me a chance to express feelings I was not quite aware of." "I felt it was educational to me even though I was emotionally drained." Based on these results, our impression is that while concern for the patients' welfare is primary, it is not a sufficient reason for preventing or hindering carefully conducted psychosocial investigation.

Although our investigation addressed other issues (10,11), all cannot be described in detail. The authors wish to thank the physicians, nurses, interviewers, and other personnel who assisted us, as well as the sources of funding mentioned above. Much more investigation is needed to understand the complexity of how family, friends, and medical staff influence, help, or hinder the patient in adjusting to a diagnosis and treatment of cancer. The results of this study indicate possible directions for future inquiry.

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