PSYCHOSOCIAL VARIABLES ASSOCIATED WITH THE EXCEPTIONAL SURVIVAL OF PATIENTS WITH ADVANCED MALIGNANT DISEASE

Paul Charles Roud, MEd, EdD
Amherst, Massachusetts

This study identified psychosocial variables associated with the exceptional survival of nine cancer patients diagnosed as terminal. During open-ended interviews, subjects described their behaviors and emotions following the onset of disease and articulated personal explanations for their survival. Despite the methodological limitations inherent in this type of research, the similarity of the subjects' responses was compelling.

All subjects believed that there was a direct relationship between the outcomes experienced and their psychological states. They remained confident that they would not die, and asserted that these positive expectations were critical to the healing process. The report by subjects that they experienced major psychosocial changes in the months following their prognoses presents a serious challenge to the conclusions of a related study.

The subjects assumed responsibility for all aspects of their lives, including recovery. Thus, medical personnel were often used as consultants. All patients established a physician relationship characterized as trusting, meaningful, and healing. They indicated an intense desire to stay alive. Unlike their attitudes before illness, once the patients were confronted with the prospect of death, life suddenly became very precious.

Many physicians and other practitioners have probably contemplated the psychosocial variables associated with the cancer patient who experiences an exceptionally favorable course of illness. The rare patient who survives what is usually thought to be a terminal cancer offers a unique opportunity to study these variables. With a few limited exceptions,[1-3] research has not systematically investigated individuals whose positive outcomes could not have been predicted by the present state of medical science. Apparently, no prior studies have asked the survivors themselves how they would explain their extraordinary results.

The following study identified and analyzed the psychosocial factors associated with the survival of nine patients with advanced malignant disease. The premise is that the experiences of individuals who survived (despite expectations that they would die) represent an original, potentially valuable source of information. The study does not maintain that the variables cited caused or even contributed to the patients' exceptional results. The intent, given the dearth of previous research in this area, is to indicate variables that warrant further investigation.

METHODOLOGY

Six physicians, each one situated in a different

From the University of Massachusetts, Amherst, Massachusetts. Requests for reprints should be addressed to Dr. Paul Charles Roud, 370C Montague Road, Sunderland, MA 01375.

medical setting, provided the researcher with access to cancer patients whose survival they considered extraordinary. These potential subjects were interviewed and asked to discuss in detail their experiences with cancer. The open-ended interviews sought to determine how the patients accounted for their unusual results as well as their perceptions of the importance of specific variables suggested by the literature.

The subjects' physicians provided background information and were asked to respond to the following question: "When the patient's diagnosis was confirmed, what was the likelihood, according to medical consensus, that the patient would live* as long as he or she had survived already?" The physicians' assigned probabilities of patient survival are listed in Table 1.

Another means used to establish the subjects' exceptionality was their self-report. In the interviews, all subjects report being told by at least one physician that they would die from their cancer in the near future.

TABLE 1. PHYSICIANS' ESTIMATES CONCERNING PROBABILITY OF SUBJECT SURVIVAL

Subject Number	Probability of Survival
1	$P \leq .001$ (First physician)
	$P \leq .001$ (Second physician)
2	$P \leq .001$
3	$P \leq .001$
4	$P \leq .01$
5	$P \leq .01$
6	$P \leq .05$
7	$P \leq .05$
8	$P \leq .1$
9	$P \leq .25$

SUMMARY OF REPRESENTATIVE CASES

Subject 1. This 54-year-old man received a diagnosis of meningeal carcinomatosis more than four years ago. According to one physician providing information about the case, "The pathology of his spinal column was reviewed both locally and by a national expert—both of whom concurred on the diagnosis of cancer. . . . He was treated once with chemotherapy and then with radiation to the brain and spinal cord." The patient was admitted to a hospice program for terminal care, and an acupuncturist provided palliative treatment. (He was subsequently the first individual ever to be discharged alive from this hospice.) The patient has steadily improved "despite the absence of further therapy." At present, there is no evidence of cancer. After the onset of cancer, the patient did retire from his job, but he has recently begun to perform moderately heavy physical labor.

Subject 2. This 63-year-old male asbestos worker received a diagnosis of lung cancer with tracheal involvement more than eight years ago. Initially, he was treated with a curative high dose of radiation, but after three months of radiation treatment, he developed brain metastasis and received a palliative dose of radiation. His oncologist stated: "In a most unusual fashion, the patient has remained well without evidence of disease since then, now seven years later (expected survival time with brain metastasis is only four months)." The patient, who has retired with disability, is ambulatory, but less active than he was prior to disease onset.

Subject 5. This subject, a 35-year-old woman with undifferentiated lung cancer, inoperable because of mediastinal nodal involvement was diagnosed more than six years ago. She completed only 25 percent of the recommended radiation treatment and began an extreme diet "therapy." She has had two recurrences; after each she agreed to some radiation, but terminated those treatments prior to completion. According to her physician, since the second recurrence (more than three years ago), "She has usually remained controlled, and has given up diet or other quackery as therapy. She does allow herself to be followed by myself on an occasional basis." Though her strength is less than it was prior to disease onset, she essentially leads a normal life as a homemaker and mother.

Subject 7. This 57-year-old woman with inoperable lung adenocarcinoma was diagnosed seven years and eight months ago. She received radiation, but experienced only minimal symptoms due to the treatment. Her radiation oncologist reported

*Although using survival as a criterion tends to be highly functional, the exceptionality of many patients is understated. Many are in good health, and a majority are reported to be in complete remission or cured.

that the patient "was told that she was incurable." He does state, however, that currently "There is no evidence of cancer and the patient is now well almost eight years later." The subject suffers from arthritis of the cervical spine, but she did report an exceptionally active social life.

DISCUSSION

Belief in Recovery

In light of the predictions of imminent death, the subjects expressed remarkable belief in their ability to survive. One subject who was out chopping wood the first time the researcher called to schedule an interview was unequivocal: "I never thought I wasn't going to get better." He remained confident even though two physicians independently confirmed initially that the likelihood of survival was (at best) 1 in 1,000, and treatment other than palliative care had been terminated. According to another subject who had lung cancer and then developed brain metastasis: "They told me I had lung cancer and probably wouldn't last very long. I decided for myself that they were all wrong."

It has been nine years since yet another man was told that he would die (within 6 months) from lung cancer. The sense of power indicated by this individual was so absolute that he seemed to take recovery for granted. He stated that after learning the terminal prognosis, he simply decided he was not going to die. "So I said that's ridiculous. I'm not going to have that." The physician who provided information about this patient wrote, "His recovery is nothing less than miraculous."

It does not appear that subjects were denying their cancer or its seriousness; they understood that most people with similar afflictions do die. Instead, they were affirming their belief that the disease would not kill them.

Although the benefits of hopeful feelings upon a course of illness have not been established, some researchers suggest a relationship between hopelessnes and cancer development. Schmale and Iker[4] predicted with significance the presence of uterine cancer using the criterion of subjects' feelings of hopelessness. Greene, Young, and Swisher[5] found that the separation from a significant object or goal, followed by feelings of hopelessness, may be one of the factors that determines the development of lymphoma or leukemia.

Subjects not only believed they would survive, they were adamant that their hopeful feelings made an essential contribution to their positive results. For example, one subject stated that when he was most ill (his lung cancer had metastasized to his eye), he deliberated between going to Mexico for laetrile or to the Simonton Cancer Clinic in Texas. He chose the clinic, but in retrospect he suggested that it really did not matter: "All that's required is your belief in the approach you choose and that particular system will work for you." Even the two subjects who thought that God had intervened to save them maintained that belief in survival was essential: "If you ask God to help you, He's going to help you. But you have to believe He's going to help you."

Research concerned with the placebo effect suggests the potential therapeutic benefits of positive belief. Cousins[6] asserts that placebos can be conceptualized as the medium through which the body converts "hope into tangible and essential biochemical change." Since most individuals tend to be bound by the "illusion of material intervention," it becomes necessary to put one's faith in something concrete that can act as "an emissary between the will to live and the body." A female subject explained the function of her own behavior in a similar manner. Shortly after diagnosis, she implemented five alternative approaches simultaneously. She explained: "I think I needed those therapies. I hung on to the therapies and attributed to them a certain power that was in fact my own power, but I didn't have the confidence to stand up and claim my own power. I needed them as building blocks to regain my confidence."

Positive Intentionality

Subjects indicated that a hopeful attitude was not a mind set that merely happened to them. After the onset of disease, they assumed responsibility for all aspects of their lives. Creating and maintaining an optimistic life stance was an active, willful process. The response of the following female subject was representative: "When I think about my illness, I just distract it, and knock it down to not get depressed. I just try and pick myself up. I never dwell on it. Even when I have pain,

I just chalk it up and say, 'Well, we all have to suffer here.' ''

Subjects worked to control their attitudes; they also deliberately shaped their environments. They were no longer willing to engage in activities or to be with people whom they did not genuinely care about. The illness seemed to free them to finally lead the lifestyles that they had always wanted to. For example, one male subject left a job he had disliked for 35 years; another moved from the city and bought a farm; one salesman quit his job to become a jazz musician; and a female subject became a ''born-again'' Christian.

Following the development of cancer, survivors also made changes in their interactional styles that enabled them to form better relationships than ever before. Their relationships were more trusting and intimate as subjects reported greater facility at communicating their emotions, especially angry and loving feelings. A middle-aged survivor explained the nature of his changes:

> My relationship with everyone that I cared about improved. My sensitivity, my level of awareness, my ability to be with other people just skyrocketed. I made incredible growth in that way.
>
> I used to cover up my feelings. Now there are no pretenses. My feelings are right on my sleeve. When I'm angry, you'll know it; if I'm simply displeased, you'll know it. If I'm feeling loving, you'll know it. What I'm thinking, I'll share.

In contrast to the experiences of these cancer patients, LeShan and Worthington[7] found that the typical cancer patient had difficulty developing intimate relationships. In their study of 250 cancer patients, subjects had life history patterns of impaired emotional expression. Communication of hostile feelings was especially problematic. The Simontons and Creigton[8] contend that individuals who hope to recover from life-threatening cancer must become more assertive in their expression of anger.

Doctor-Patient Relationships

All subjects enjoyed a very important and highly satisfactory relationship with at least one physician involved in their treatment. Consistent with other aspects of their lives, survivors are instrumental in creating these meaningful relationships. They viewed themselves as partners in the task of healing, but primary responsibility for recovery remained theirs. The subjects maintained close vigilance over their medical treatment, frequently using medical personnel as consultants.

Subjects sought practitioners who were caring, genuine, honest, and respectful. Physicians who met these criteria were said to be healing. One subject described the satisfying nature of his relationship:

> He's modest, he's unassuming, he tries to learn from his patients, and he never makes arbitrary statements. If a question arises that is a matter of judgment, he'll say what he thinks ought to be done, explain the reasons why, but then leave you free to make your own decision. Since we're free to make decisions, we follow his judgment. He understands my desire to take responsibility for my illness. It has been a very happy relationship.

Subjects believed that their positive medical relationships contributed to healing. An elderly female subject stated: ''They don't treat this place like a cancer clinic. Here we are friends, like next-door neighbors, and that helps. Yes, it helps a lot.''

For a few subjects, the relationships they established with their physicians actually became a reason why they wanted to live. A male patient with a poor marital relationship and a limited social-support network explained: ''There's another reason why I want to hang around [survive]—my doctor is so proud of me living all this time. He brings me downstairs and shows me to the girls [female secretarial staff]. He always asks me if there's anything I need.''

Another subject was treated at this same clinic for advanced breast cancer. She was asked if she thought the personal relationships she had developed with hospital staff influenced her disease: ''Oh yes! Oh yes! All these people are very caring. The girl at the desk calls me by my first name. It makes you feel good and you want to continue improving.''

The Desire to Live

Subjects directly verbalized or indicated through their actions an intense desire to live. One subject described his reaction to the oncologists' recommendations for chemotherapy treatment:

> The oncologists would say, 'Look, if you go for this treatment then maybe we can give you three or four more years.' But they didn't understand. I'm saying,

'Goddamnit! You're talking about giving me three or four more years. I'm talking about beating the rap. I'm going for a win! I'm not going for three or four more years. That doesn't interest me!'

Some of the subjects were able to extract, examine, and discuss the nature of their desire to live. For one patient, the desire to live was an energy source:

I can remember lying in the hospital in Boston with my throat cut out and all the tubes coming out of me. I was sinking, succumbing, and thinking to myself, 'What's the point of it all. It's too much to overcome.' Then, all of a sudden I could hear a click inside of me—like throwing a toggle switch. I could hear that switch go on and suddenly I began to energize. I sat up and said to myself, 'C'mon! You figure out a way. Get around it. Go through it or go over it! You can do it!'

Three subjects discussed the struggle to stay alive as a fight or a battle. One of the three suggested that this orientation is shared by all exceptional survivors: "A basic common denominator is a willingness to fight, a scrappiness, an unwillingness to lay down and die."

The desire was not to merely stay alive. They wanted to be healthy and active. Subjects were seeking rich, full lives.

The individuals reported that since their illness, they are now much more grateful to be alive. One woman had great difficulty breathing after her lung cancer had grown up her trachea. Her family was told to prepare for her imminent death. This woman, who now leads a relatively normal life as a homemaker and mother, expressed a new appreciation about what's important: "Really, when you're breathing, you have everything that counts. When you're getting close to death, every minute counts."

According to another survivor, life was filled with pain until she contracted cancer. The shift in perspective is profound: "Believe me, it's very different now. Everyday is beautiful. I just don't have the time to cry anymore. I used to wake up and feel 'Oh hum, another day.' Now I wake up and say, 'Thank you, God.'" Like the rest of this extraordinary group, misgivings for the past and anxiety about the future were greatly reduced.

Individuality of Experience

To make sense of the experiences, the commonalities among subjects has been the focus of this analysis. Many shared factors do emerge when exploring the group's collective experience. The effort to generalize from the subjects' varied experiences may, however, minimize and even distort the very distinct nature of each subject's healing process. For each subject adopted certain behaviors and beliefs unlike any of the others. To exemplify, practically all subjects described family relationships that were encouraging, nurturing, and respectful—relationships that seemed idyllic in many ways. But the one exception said that he and his wife fought constantly and that his son had wished him dead. Another example: subjects as a group were adamant about the need to be informed about their treatments. The lone exception, however, said that she simply put all her faith in her doctors and never asked them any questions. Similarly, there was consensus of opinion among subjects that their diet played a significant role in their exceptional results. They all made radical dietary changes, eating much more nutritiously than previously—except one. An interview with this particular survivor (of lung cancer) was held at a restaurant. The researcher watched as he ate a breakfast of coffee, white toast, eggs, and bacon, and then lit up a cigarette.

When subjects were asked, "What advice would you give to other seriously ill cancer patients?", they declined to make specific recommendations. Even though they adamantly believed in the efficacy of the plans they adopted, they did not assume that their approach would work for anyone else. Survivors believed that they discovered what would be healing through a process of introspection and intuition. They suggested that others who are close to death must look within to find their own answers.

IMPLICATIONS

The methodological limitations of this study are apparent. Although the exceptionality of survival is established, there was no control group to act as a source of comparison. Also, the patients were asked to provide, through self-report, the psychosocial data after their exceptionality had been established. Thus,the subjects' recollections of their attitudes and behaviors may have been distorted by their positive results. Since the purpose of this study was to understand the psychosocial experiences of truly extraordinary survivors, in order to correct the problems cited, it would have been

necessary to gather psychosocial data for thousands of patients with advanced cancer.

The highly publicized study by Cassileth et al[9] was an ambitious effort in this direction, although their sample population included "only" 359 subjects. Unfortunately, the design appears so flawed that the researchers' conclusion that "the inherent biology of the disease [advanced cancer] alone determines the prognosis" is invalidated. Because the researchers collected the psychosocial data at only one point in time—shortly after diagnosis—the underlying assumption, then, is that psychosocial status remains relatively constant over the course of illness. In the present study, however, it was apparent that the psychosocial states of survivors changed dramatically in the months following their diagnoses. Their initial response was in no way representative of their psychosocial status months later.

The issue is reflected by a subject who described his reaction during the weeks that followed the diagnosis: "I did my share of crying including the 'why me' and 'oh god.' Everybody goes through that." Within months, however, this patient's feelings of helplessness had disappeared, "I realized that I didn't have to accept the prognosis."

An elderly subject explained the same phenomenon: "At first I felt well, if my time had come then it would behoove me to recognize it. It took me a while to come to the conclusion that I really did want to live." A variable that differentiates survivors from nonsurvivors may be their ability to psychologically change after disease onset—a factor never considered by Cassileth et al.[9]

Clearly, the purpose of the present study was exploratory: Can the experiences of exceptional survivors provide new clues about the relationship between psychosocial factors and cancer? The commonality of the subjects' responses does suggest that certain factors warrant further investigation. The variables identified in this study need further refinement with an eventual goal of determining whether a causal relationship exists between these factors and the course of illness. Studies that predict patient outcome from the patient's psychosocial data will help assess the functional utility of these factors.

Psychosocial variables hypothesized to influence cancer growth could be manipulated for experimental purpose. For example, one group of seriously ill cancer patients could be provided information that was accurate but still enabled them to maintain hopeful feelings. They might meet with, or read accounts of, other individuals who survived illnesses similar to their own. This sample population would be encouraged, through counseling or other means, to experience the preciousness of life and more fully activate their desire to live. Medical personnel could be given more time to spend with this experimental group than is usually possible. Staff would thus be able to develop more personally meaningful relationships with these patients. Morbidity rates (or other patient outcome criteria) of the experimental group would be compared with a control group.

Although subjects are unequivocal that certain psychosocial variables contributed to their healing, there is no direct evidence that these factors do influence cancer growth. Future research will determine the significance, if any, of the variables cited. Even before such research is conclusive, however, full consideration of psychosocial variables could be incorporated into treatment plans. There are no toxic side-effects, and the potential exists to improve the quality of the patient's life.

Acknowledgment

Paul Berman, MD, David Sherman, MD, John W. Wideman, EdD, and Norman Cousins gave their assistance to this study.

Literature Cited

1. Kennedy BJ, Tellegen A, Kennedy S, Havernick N. Psychological response of patients cured of advanced cancer. Cancer 1976; 38:2184-2191.

2. Ikemi Y, Nakagawa S, Nakagawa T, Mineyasu S. Psychosomatic consideration on cancer patients who have made a narrow escape from death. Dynamic Psychiatry 1975; 75:77-92.

3. Weinstock C. Notes on "spontaneous" regression of cancer. J Am Soci Psychosom Dent Med 1977; 24:106-110.

4. Schmale AH, Jr, Iker HP. The affect of hopelessness and the development of cancer: 1. Identification of uterine cervical cancer in women with atypical cytology. Psychosom Med 1966; 28:714-721.

5. Greene WA, Jr, Young LE, Swisher SN. Psychological factors and reticuloendothelial disease II. Observations on a group of women with lymphomas and leukemias. Psychosomat Med 1956; 18:284-303.

6. Cousins N. Anatomy of an illness. New York: WW Norton, 1979.

7. LeShan L, Worthington R. Some recurrent life history patterns observed in patients with malignant disease. J Nerv Ment Dis 1956; 124:460-465.

8. Simonton OC, Matthews-Simonton S, Creigton JL. Getting Well Again. Los Angeles: JP Tarcher, 1978.

9. Cassileth BR, Lusk EJ, Miller DS, et al. Psychosocial correlates of survival in advanced malignant disease? N Engl J Med 1985; 312: 1551-1555.