The Role of Behavioral and Psychosocial Science in Reducing Cancer Morbidity and Mortality

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ABSTRACT

Behavioral and psychosocial science has the potential to contribute much to the overall effort to reduce cancer morbidity and mortality and to improve the quality of life for cancer patients and their families. However, for a variety of reasons, including a lack of sustained funding for research and training and a lack of confidence by some in the potential payoff for investments in the area, this potential has not only not been realized but also not been adequately explored. A special subcommittee of “The March” Research Task Force studied research in this area and issued a report making several recommendations for future funding for psychosocial and behavioral research in cancer. This article reports those recommendations and the reasons the committee supported them. The Oncologist 2000;5:263-266

Cancer is the second most common cause of death in the United States—behind only heart disease—and cancer is likely to surpass heart disease in the near future. Since 1990, approximately 13 million new cancer cases have been diagnosed. In the year 2000, it is estimated that approximately 1,500 people per day will die of cancer. Ultimately, experts predict that one of every four Americans will die of cancer [2]. The ubiquitousness and terror-inducing nature of cancer poses a broad spectrum of issues to both patient and physician: prevention, early detection, treatment and the symptoms induced by it, rehabilitation, and family and end-of-life concerns. Standard medical education typically prepares physicians, nurses, and other medical personnel to handle a limited subset of these issues. Behavioral science, however, can provide a link to the entire spectrum of these issues.

Unfortunately for both patients and practitioners, most basic medical researchers, the public, and even some behavioral scientists regard psychosocial and behavioral research as a “soft science” that is of limited practical utility in reducing cancer morbidity and mortality. The premise of this article is that this attitude is wrong. Data show that behavioral and psychosocial research holds significant promise for preventing cancer and improving the lives of cancer patients and their families. For example, behavioral and psychosocial research can play a key role in developing effective strategies that will encourage people to adopt healthier lifestyles. It can help ensure that a patient’s quality of life is properly taken into account in the increasingly complex decision-making process involved in weighing different treatment options. It can provide alternative approaches to reducing specific symptoms including pain, nausea, fatigue, and depression that may have fewer undesirable side effects than currently prescribed medications. It can aid in the development of effective strategies to persuade members of minority groups and other underserved populations to undergo critical diagnostic tests and participate in clinical trials. In the case of the terminally ill, behavioral scientists can aid the medical staff in efforts to maximize patients’ quality of life.
In spite of this promise, funding for behavioral research has been a comparatively low priority for the federal government and for many private cancer research organizations (see endnote). Nonetheless, the limited behavioral research that has been done clearly demonstrates its potential impact. Consider, for example, the following:

Research done at Stanford has shown that women with breast cancer have a higher quality of life if they participate in active support groups, as compared to those who do not, and also survive significantly longer [3]. This and similar studies are the basis for the American Psychological Association’s Breast Cancer Demonstration Project, which is designed to move these interventions into real-world health care systems and measure their effects.

A prospective study of how patients decide whether to undergo a genetic test for BRCA1, a gene associated with increased risk of breast, ovarian, and colon cancer in women and prostate and colon cancer in men, has provided valuable information about how people respond to new genetic tests [4]. The investigation, conducted by researchers from several universities, identified both the major barriers to undergoing testing and the psychological effects of taking the test. It found that major barriers include questions about the accuracy of the test and concerns about losing health insurance. The major effect of taking the test was a decrease in the incidence of depression among those testing negative without an increased negative affect in those testing positive.

Most women with gynecological cancer receive radiation therapy, which frequently causes changes that produce sexual dysfunction. Methods for preventing these problems, including certain exercises that dilate the vagina, have been developed, but compliance is generally poor. Research done by a group of Canadian scientists has demonstrated that a simple psychoeducational program can significantly improve compliance and reduce the side effects of the treatment [5].

To test these and other findings in clinical trials, and to generate additional behavioral research of quality and impact, fundamental changes are needed in the amount of funding made available to behavioral scientists, the types of behavioral research funded, and the training opportunities offered to new and established behavioral researchers. The Psychosocial Research Working Subcommittee of “The March” Research Task Force [1] reviewed current governmental and private policies toward funding for psychosocial research in the treatment of cancer. As a result of its findings, it developed the following recommendations:

If we are to prevent cancer, we must convince people to adopt healthy lifestyles that include, for many, changing longstanding eating, drinking, and smoking habits, as well as other behaviors. We need a greater understanding of the basic principles of human behavior and behavior change in order to develop effective techniques that will enable people to make these changes. This will require increased support of basic behavioral research. We need increased insights into the factors leading to addictive behavior before we will know how to make the long-lasting behavioral changes that affect cancer incidence. For example, there are clearly different levels of addiction to drugs like nicotine. If we can discover effective ways to differentiate between those individuals who have a strong physiological addiction to nicotine from those who do not, it may prove possible to develop more effective methods for inducing both types of individuals to stop smoking.

In order to create the critical mass of researchers needed to make significant progress on cancer-related problems, we should create multidisciplinary research teams at the nation’s cancer centers. Such teams would include both basic and clinical biomedical and behavioral researchers. They would focus on specific cancer problems that require diverse expertise to solve, such as many problems of prevention, early detection, compliance, and rehabilitation, and the interaction of these problems with the quality of a person’s life. The concentration of funding on fewer but larger programs will allow the best researchers to concentrate their efforts, and thus have a significant impact on obtaining and applying new knowledge in the area. Such an effort would also encourage promising young investigators to enter the field.

Behavioral interventions for the treatment of cancer generally have been tested with small numbers of subjects, which limits confidence in the results and their generalizability. To address this problem, cooperative group studies should be initiated that combine data from large numbers of patients over a wide geographic area. This approach has worked well in testing new biomedical cancer treatments and interventions and could work well for behavioral research. Two approaches are possible: A) the creation of a new behavioral and psychosocial clinical trials program, or B) the inclusion of behavioral studies in the current, highly successful Cooperative Group Clinical Trials Program or at least the employment of the extant Cooperative Groups infrastructure (e.g., statistical centers, patient access procedures, etc.) to launch behavioral studies. An example of a potentially important clinical trial in the behavioral area involves the research mentioned earlier by Spiegel and his colleagues, who showed that breast cancer patients have a higher quality of life, and may live longer, if they participate in an active support group [3]. Currently, a research team is running cooperative clinical trials that attempt to replicate these results in hospitals around the country. The outcome of these trials should provide important information on the general applicability of this approach. This type of a cooperative group program is needed to assess a large number of behavioral interventions.
Decisions that physicians and patients must make regarding the choice of optimal cancer treatments are getting more and more complex. In the case of breast cancer, for example, the doctor must consider a number of possible treatments, including a modified radical mastectomy, lumpectomy with or without auxiliary node sampling plus radiation, and, for those with appropriate risk for distant metastases, adjuvant therapy. Even if the different treatments produce similar results in terms of disease progression and treatment outcome, each has different advantages and disadvantages, including different impacts on a patient’s self-esteem and subsequent quality of life. Behavioral scientists can help develop a framework to assist doctors in weighing these factors and provide recommendations for how best to ascertain patients’ preferences. Before this can be done, however, psychosocial researchers need to know more about how to assess the amount and kind of information and the degree of involvement in the decision-making process that various patients and their families prefer.

Minorities and other underserved populations have special needs when confronted by cancer. They tend to seek medical attention later in the course of the disease and are less likely to change their behavior to improve the effect of treatment or to reduce their risk of getting the disease. There are a number of theories about why this is the case, but little research. More effort is needed to determine the way in which minorities decide to seek treatment for different forms of cancer. This research is urgently needed to reduce the toll that cancer takes in underserved communities. Overall rates of cancer mortality vary considerably among racial and ethnic groups: African Americans are 33 percent more likely to die of cancer than are Whites, and 50 percent more likely to die of cancer than Hispanics, Asian/Pacific Islanders, and American Indians [2]. Determining the role that both cultural differences and economic factors play in individual attitudes about disease and treatment is crucial for the success of any effort to influence the behavior of these groups. Psychologists at the Cancer Research Institute of Hawaii (http://www2.hawaii.edu/crch), for example, developed a program based on the Hawaiian value of kokua, which means “helping others without expecting help in return,” designed to encourage native Hawaiian women to seek cancer screenings. The program increased cancer screening rates in the participating community [6].

Pain, nausea, fatigue, depression, and other symptoms commonly have a psychological component and have an enormous impact on many cancer patients. Despite this fact, research on the methods of reducing or preventing these symptoms often fails to consider and address the role psychological factors play in their genesis and course. This failure in part results from the lack of support for behavioral research and in part from the lack of multidisciplinary approaches to research or clinical approaches to symptom management. There are examples of the potential importance of such an approach. For instance, the standard chemotherapy drugs used in the 1980s frequently produced unpleasant side effects that compromised patients’ quality of life and sometimes led to the use of dosages that were less than optimal. Research conducted at several institutions proved that as much as one-third of the incidence of nausea and vomiting associated with chemotherapy was the result of maladaptive learning [7]. Further studies demonstrated that behavioral techniques were effective in reducing nausea and vomiting associated with these treatments [8]. Although a new crop of antiemetic treatments are reducing the likelihood that patients will experience significant nausea and vomiting following chemotherapy, recent studies have found that chemotherapy still causes nausea in many patients and that behavioral interventions are useful adjunctive techniques [9].

Priorities change dramatically when a patient is approaching the end of life. Behavioral research is urgently needed to improve the quality of life of terminally ill individuals, including cancer patients. At the end of life, it often no longer makes sense to use procedures that inflict pain, induce confusion, nausea, fatigue, or depression. Instead, it is important to develop the means to relieve or prevent these symptoms, even if the underlying disease cannot be cured or arrested. Some progress is being made in this direction, but much more remains to be done to relieve the suffering of the dying and their families.

In order to address the issues mentioned above, and many others, we need to train more researchers in psychosocial and behavioral oncology research and practice. Funding for pre- and postgraduate training in the field must be expanded to address the increased demand for their expertise that will be created if our recommendations are implemented. In addition, medical staff at the national cancer centers often would benefit from a general understanding of the basic principles of behavioral science. This can be assured by putting in place training programs that cover the psychological, social, and behavioral issues involved in the treatment of cancer patients as well as including psychosocial and behavioral questions on medical board examinations.

Adoption of these recommendations will promote quality behavioral and psychosocial research, generate important new approaches to prevent cancer and reduce its negative impact on patients’ lives, and attract some of the best young scientists into the field of behavioral science. The recommendations address a long-standing need and, if implemented, will play an important role in our ultimate victory in the war against cancer.
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ENDNOTE

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REFERENCES
