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To cite this article: James R. Zabora & Matthew J. Loscalzo (1996) Comprehensive Psychosocial Programs: A Prospective Model of Care, *Oncology Issues*, 11:1, 14-18, DOI: [10.1080/10463356.1996.11904589](https://doi.org/10.1080/10463356.1996.11904589)

To link to this article: <https://doi.org/10.1080/10463356.1996.11904589>



Published online: 18 Oct 2017.



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Comprehensive Psychosocial Programs: A Prospective Model of Care

by James R. Zabora, M.S.W., and Matthew J. Loscalzo, M.S.W.

Cancer and its related treatments disrupt every aspect of patients' and families' lives and challenge their psychological, social, spiritual, and financial resources. As cancer patients and their families struggle to confront a series of difficult decisions, they must also cope with the fear, anxiety, anger, sadness, and depression that cancer creates. The diagnosis of cancer generates a greater sense of dread than other life-threatening illnesses with poorer prognoses.¹

Evidence strongly suggests that patients with elevated levels of psychological distress may experience poorer treatment outcomes, possess greater levels of dissatisfaction with health care, and incur increased health care costs.²⁻⁴ Psychosocial distress left unattended may result in a crisis event that triggers a referral for immediate intervention.

A reactive system in which cancer centers and community hospitals do not attend to a patient's psychological distress inevitably consumes greater resources and generates higher costs than a system in which providers do address a patient's psychosocial needs. Yet, most cancer centers and community hospitals refer to social work or psychiatry only if the patient's distress has become so severe that it is unmanageable for the team.⁵

Psychological distress can affect compliance with drug regimens, appointment keeping, and making decisions about treatment alterna-

tives.^{6,7} Noncompliance rates, which range from 20 to 80 percent, can lower quality of life and affect survival outcomes.⁸ These figures suggest that a small investment of funds early in treatment to address psychological concerns may actually reduce costs by decreasing rehospitalizations and overall use of health care resources.

State-of-the-art psychosocial programs integrate a range of interventions including education, support groups, short-term counseling, and psychotherapy. These interventions can help address the psychosocial needs and concerns of cancer patients and their families.

COPING AND ADAPTATION

To design and implement effective psychosocial programs and services for cancer patients and their families, health care providers must understand the dynamic nature of coping. Coping can be defined as cognitive, behavioral, or social strategies that patients and families use to bring about relief in relation to a perceived threat or a demand and to restore equilibrium.⁹ A diagnosis of cancer is not the only threat; the demands associated with treatment are also threatening and indeed may be insurmountable for some patients and families. Although clinical observations and research confirm that the majority of patients cope effectively with the diagnosis and treatments, it is also clear that a significant percentage of patients do not.

Patients exhibit coping through verbalization or behavior that serves to resolve problems and decrease stress. Coping strategies include confrontation, humor, acting out, and withdrawal. Table 1 on page 16 details the fifteen primary coping strategies as defined by Weisman.¹⁰ Clearly some strategies are more effective than others. While anger or hostility, for example, may be an

appropriate emotion, neither effectively solves problems nor provides relief from distress. Patients with ineffective problem-solving techniques benefit from psychosocial interventions that teach and promote such strategies as seeking information and sharing concerns.

Evidence suggests that a patient's initial adaptation to a cancer diagnosis is significantly influenced by psychosocial factors that the patient brings to his or her cancer experience. Table 2 defines these variables under the general headings of social support, past history of functioning, current concerns, and key demographic variables.¹¹ Psychosocial providers can use these variables to form patient profiles that help predict which patients will effectively adapt to their diagnosis and treatment as well as which will experience significant difficulty in their adjustment. Techniques such as psychosocial screening can be used to quickly identify patients who may experience a higher level of distress.

Two brief patient profiles may help illustrate the diversity of patients' responses. In the first example, a 60-year-old male recently diagnosed with colon cancer reports in the screening questionnaire that he is married, lives with his family, and has a number of other family members in the vicinity. Although he reports periodic episodes of depression, his mood is positive, and he has never required mental health services. The patient describes a history of alcoholism, but is now recovering and has actively participated in Alcoholics Anonymous for ten years. He is generally optimistic about the outcomes of treatment and has minimal regrets concerning how he has lived his life. Current concerns are minimal as he anticipates beginning treatments.

In the second example, another 60-year-old patient is a widower

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who lives alone and has only three other family members living nearby. A history of depression has resulted in a prior psychiatric hospitalization, and he continues to receive care for recurrent changes in his mood. As a result of these factors, he is generally pessimistic about the outcome of his treatment and is rather indecisive concerning the alternatives that have been presented to him. Despite three discussions with his physician and additional written information, the health care team awaits his decision as to whether he wishes to begin chemotherapy.

Each of these patients will require different levels of resources and staff time. The first patient example may be best served by an early interaction with a colon cancer survivor who can provide useful information as the patient approaches chemotherapy. Patients who are similar to the second profile will experience a gradual increase in their level of psychological distress and consequently may require short-term psychotherapy.

Unfortunately these needs are not often readily apparent early in the treatment process. Most often patients actively conceal their distress from their health care providers to help ensure that physicians and nurses maintain their focus on the treatment of the cancer.¹² However, the distress in these patients will

increase over time and could result in a series of crisis events.

ADAPTING ALONG TWO CONTINUUMS

Health care providers must be aware of two salient timelines, or continuums, that relate to patient and family adaptation to cancer and treatments (Figure 1). The first timeline is the *disease continuum*. Patients' needs vary and fluctuate significantly as they move from the point of diagnosis through treatment and into remission.¹³ For a number of patients the disease continuum includes recurrent disease and entry into terminal care. For families, the disease continuum includes bereavement for an indefinite period of time. The second continuum relates to the *level of psychological distress* that each patient experiences as he or she moves along the disease timeline. Prevalence studies of psychological distress indicate that 25 to 30 percent of all newly diagnosed and recurrent patients experience significantly elevated levels of emotional distress, while as many as 47 percent have a psychiatric diagnosis.¹⁴⁻¹⁶ In all probability, these patients enter their cancer experience with significant distress that is actually related to preexisting psychosocial problems.

Clearly, the diagnosis of cancer generates significant distress for

all patients. The majority, however, learn to live with cancer, address the consequences, and solve the multiple problems that confront them. Overall, the psychosocial needs of patients and families vary significantly based on patients' level of psychological distress and their exact point on the disease continuum. The provision of services as early as possible on the disease continuum may be less stigmatizing to the patient and more easily incorporated into the comprehensive medical care of the patient.¹⁷

The alternative is to allow these patients to suffer needlessly through treatment as their distress increases. Unfortunately, the intensity of their distress results in a crisis event manifested by symptoms such as severe depression or suicidal thoughts, which trigger a referral for immediate psychosocial intervention. This reactive model of psychosocial care forces patients to "medicalize" their emotional concerns and to manifest their distress as a crisis in order to receive assistance. This reactive system will inevitably consume more resources and therefore generate higher costs.

FAMILIES: CRITICAL SOURCE OF SUPPORT

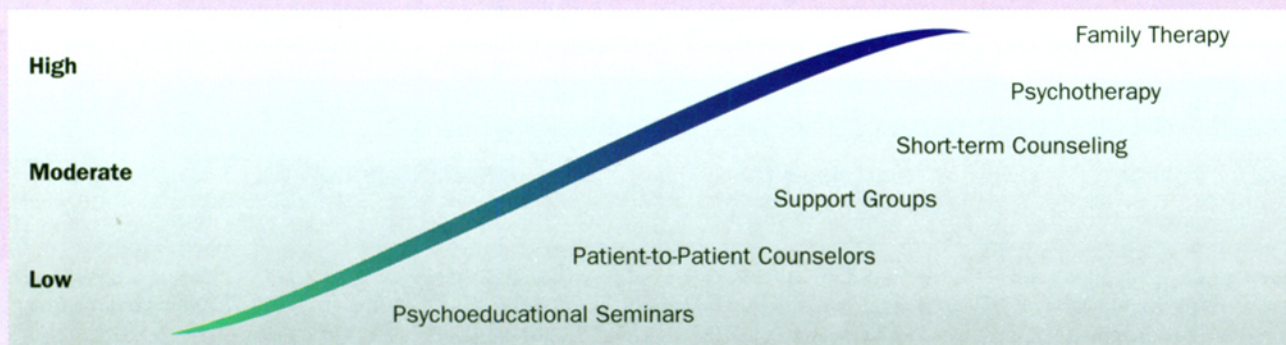
Families simultaneously struggle to adapt and cope with the many challenges associated with cancer and its

Figure 1. Continuums of Care for Cancer Patients and Their Families*

Disease Continuum

Diagnosis	Treatment	Survivorship	Recurrence	Terminal Care	Bereavement
Crisis Intervention	Cognitive Behavioral Intervention	Psychoeducational Seminars	Psychotherapy	Palliative Care	Short-term Therapy

Distress Continuum



* These are potential interventions at specific points on each continuum. For example, patients may benefit from psychotherapy at any point on the continuum.

treatments. The family often serves as the primary source of support for the patient—a buffer against stress and a facilitator for effective decision making. However families also exhibit a significant variation in their ability to adapt and respond to cancer.¹⁸ If they do not adapt, the health care team loses a significant resource in the overall care of the patient. Again, early intervention can address family concerns on behalf of the patient to reduce resource utilization and overall costs.

Olson's Circumplex Model of Family Functioning¹⁹ provides a framework to understand and examine family behavior (Figure 2). Two critical constructs—adaptability and cohesion—help to explain families' ability to adjust to the stressors associated with cancer and their capability to provide the necessary level of support to the patient. Adaptability describes the family's ability to reorganize internal processes such as decision making, financial management, and role assignments under the threat of a significant stressor such as cancer. Cohesion quantifies the degree of emotional bonding within each family.

Both family adaptability and cohesion also fall on continuums, detailed in Figure 2. Families that fall on the extreme of either continuum may present unique behaviors, defined by the health care team as difficult or problematic. For example, the family that experiences a high level of cohesion or emotional bonding may act as though each family member is equally affected by the diagnosis; boundaries between family members are minimal. Consequently, this family may be overprotective of the patient, speak

Table 1: Coping Strategies and Their Level of Effectiveness¹⁰

MOST EFFECTIVE	INTERMEDIATE EFFECTIVE	LEAST EFFECTIVE
Confrontation	Seek information	Suppression
Redefinition	Share concern	Stoic submission
Compliance with authority	Humor	Acting out
	Distraction	Repetition compulsion
		Tension reduction
		Withdrawal
		Blame others
		Self-blame

for the patient, and demand excessive amounts of staff time in relation to their concerns about the patient. This family may find it difficult to follow inpatient unit guidelines or they may encourage the patient not to follow medical directives. These behaviors can be easily intensified by the psychological distress level of the patient as well as any emotional reactions in any of the family members.²⁰

Most often, family difficulties and problems emerge as the patient proceeds through treatment and into remission. Given dramatic decreases in length of stay, expectations of families as care givers have significantly increased. Often the expectations of families held by the health care team are relatively consistent without careful consideration of the family's actual capability to perform the role as care givers. In addition, all families experience difficulty if the role of care giving is prolonged.²¹ Families should be reassessed at six months following bone marrow transplantation to examine their level of physical and psychological fatigue. As with the patient, the same premises of early identification and interventions for families who will experience significant or prolonged distress can facilitate the delivery for care for the patient and the health care team.²² Early identification of families who may experience significant problems

is critical as the health care system increases its reliance on family members as care givers.

PSYCHOSOCIAL SCREENING

Screening for psychosocial distress offers the opportunity to identify vulnerable patients and families early in the diagnostic or treatment phases. While a number of clinicians and investigators have described screening questionnaires, words of caution are necessary. There is a tendency to incorrectly equate the terms "screening" and "assessment." Screening is a method to quickly identify which patients or families may be vulnerable to the cancer experience through the use of a standardized measure.²³ Assessment is an ongoing process in which a comprehensive understanding of key variables is examined and understood.²⁴

The first step in psychosocial assessment is a brief mental status examination that documents the quality of functioning at the time of the interview. The status of the disease, complications related to therapy, and the pharmacological interactions of chemotherapy and other medications contribute to periods of transient delirium. Altered mental status decreases the reliability of patient information.

Critical components of a psychosocial assessment include physical and psychological functioning,

Table 2: Variables Associated with Psychosocial Adaptation¹¹

SOCIAL SUPPORT	PAST HISTORY	CURRENT CONCERNS	OTHER
Marital status	Substance abuse	Health	Education
Living arrangements	Depression	Religion	Employment
Number of family members and relatives in vicinity	Mental health	Work-finance	Physical symptoms
Church attendance	Major illness	Family	Anatomical staging
	Past regrets	Friends	
	Optimism vs. pessimism	Existential	
		Self-appraisal	

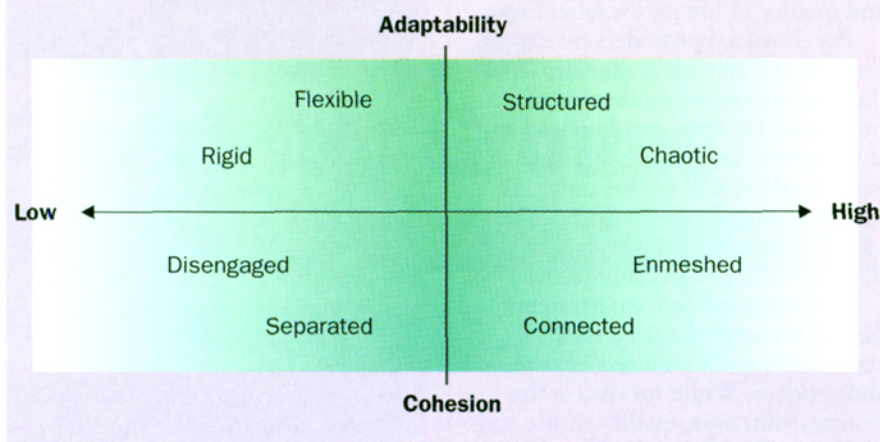
social support, financial status, and an evaluation of the meaning of disease to the patient. Inherent in these domains is an examination of sexuality and intimacy, impact on the family, spirituality, and any thoughts related to suicide. In most settings master's-prepared social workers not only complete psychosocial assessments, but they also deliver crisis intervention services and short-term counseling.

Many screening questionnaires have not been psychometrically tested for their reliability and validity. If a screening instrument is designed to identify and measure psychological distress or family functioning, it must adhere to psychometric principles. Moreover, any screening instrument should be brief so that it can be easily incorporated into ambulatory settings. Questionnaires should not take more than 10 to 15 minutes to answer; patients should be able to complete the form in waiting or examination rooms.

Specific psychometrically valid and reliable instruments and methods have been identified.²⁵⁻²⁷ However, the need continues for a brief screening instrument that can be easily and rapidly scored. Such an instrument would allow patients and families to be triaged and offered prospective services as early as possible following completion of the diagnostic phase.

Efforts continue at Johns Hopkins to develop psychosocial screening techniques to identify psychologically distressed patients during the first week of treatment in order to match them with appropriate services. Through the use of the Brief Symptom Inventory, levels of psychological vulnerability can differentiate patients by low, moderate, or high distress. Low distress patients may benefit by participation in psychoeducational programs that will reinforce their adaptive capabilities and skills. Patients with moderate distress are provided cognitive-behavioral interventions that can be used to manage symptoms such as anxiety, depression, or insomnia. High distress patients possess significant psychosocial needs and individual psychotherapy or family therapy would be the most appropriate interventions. Through psychosocial screening, all of these services can be offered prospectively as an essential component of comprehensive care. Psychosocial screening

Figure 2. Critical Variables Related to Family Adjustment¹⁹



and services can also be integrated into the delivery of cancer therapies to manage the complex needs of patients and families as they move through the diagnostic phase into one or more treatment modalities. Patients and families will continue to require support as they complete treatment, achieve a remission, or continue to struggle with recurrent disease. Potential programs across the disease continuum include crisis intervention, psychoeducational seminars, psychotherapy, and short-term therapy. Potential programs across the distress continuum include patient-to-patient counselors, support groups, and family therapy (Figure 1).

A cancer survivors' program can be incorporated into existing departments and positions. For example, a department of oncology social work can initiate and coordinate an educational seminar series that focuses on survivorship issues. Community-based professionals such as attorneys and financial planners can be recruited as volunteers to educate cancer survivors concerning employment discrimination and estate planning. Clearly defined psychosocial interventions (i.e., education, support groups, cognitive-behavioral techniques, and psychotherapy) can reduce distress and improve quality of life.²⁸

These programs of intervention increase costs. However, costs can be contained through creative program planning and management. In most clinical settings or cancer centers, psychosocial programs actually consume less than 1 to 2 percent of total allocations. Consequently, this type of investment may result in significant cost reductions later

in the delivery of cancer care and treatments. Clearly, untreated psychological distress dramatically increases total health care costs.²⁹

Alternative sources of funding such as grants, foundations, gifts, or fundraisers may be used to support new program development. In our setting, for example, a psychoeducational program that focuses on cancer survivorship primarily uses volunteers. Other program expenses such as marketing, program brochures, and educational materials are supported by gifts and contributions. A monthly prostate cancer educational and support program receives support from a pharmaceutical company. Finally, a cancer counseling center that provides psychotherapy operates on a fee-for-service basis. To provide pro bono services and to address the annual deficit, an endowment fund has been established.

In other disease populations, such as those with coronary artery disease, the role of psychological distress and its inherent ability to increase health care costs have been described.³⁰ These types of studies must also be undertaken in cancer. While psychosocial interventions have been proven to reduce distress and enhance quality of life, their ability to reduce overall health care costs has not yet been demonstrated. However, preliminary evidence suggests that a small investment of funds early in treatment to address psychological concerns may actually result in reduction of costs due to a decrease in rehospitalizations and overall use of health care resources. Data that demonstrate cost savings can help position psychosocial services for inclusion into global managed care contracts. While survival

statistics will always be a primary consideration under managed care, factors such as patient satisfaction and quality of life play a salient role.

Psychosocial providers possess the skills to provide leadership in the appropriate measurement of outcomes. However, unless leadership is provided, managed care organizations will define and measure these concepts despite a lack of expertise in instrument development and psychometrics.

The managed care environment demands comprehensiveness, continuity, and timeliness of care and services. While survival is the primary outcome, quality of life and patient satisfaction will be strongly considered. Psychosocial screening and interventions provide a unique opportunity to carefully design and provide comprehensive treatment plans that effectively address the diverse needs of patients and families as they respond to medical, psychological and social demands associated with a cancer diagnosis and treatments.

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The Johns Hopkins Oncology Center

Department of Patient and Family Services

The Department of Patient and Family Services was established in 1985 to consolidate supportive services for cancer patients and their families. Currently, six programs offer clinical, educational, and supportive services. These programs and their activities include:

- Department of Oncology Social Work—adjustment to illness, patient/family group, discharge planning, community resources
- Residential Living Program—lodging, counseling services, educational programs
- Psychosocial Research Program—patient involvement in care, return to normalcy,

and the quality of life

- Volunteer Services Program—enhance patient and family adjustment, companionship
- Cancer Counseling Center—promote long-term adjustment
- Community Services Program—screening and early detection, psychosocial support, access/advocacy/resources, education.

In addition, two new programs, the Cancer Survivors Program and the Palliative Care Program, have been developed and implemented under the direction of the Department of Oncology Social Work.

Psychosocial services are offered based on referrals from any member of the health care team or by the patient and family. Referrals for psychosocial care are often reactions by the team to significant psychological symptoms exhibited by the patient or family.

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