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## Surviving Adult Cancers. Part 2: Psychosocial Implications

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**Purpose:** To address the psychosocial implications of surviving adult cancers by a comprehensive review of the literature.

**Data Identification:** An English-language literature search using MEDLINE (1970 to 1988), *Index Medicus* (1970 to 1988), and bibliographic reviews of textbooks and review articles.

**Study Selection:** Of 103 originally identified articles, 58 that specifically addressed the stated purpose were selected.

**Data Extraction:** Four authors reviewed and critiqued the literature extrapolating the major themes on this topic.

**Results of Data Synthesis:** There is little information on the many psychosocial variables that affect an adult's long-term cancer survival trajectory. Collation of data identified the following significant psychosocial themes: fear of recurrence and death, relationships with the health care team, adjustment to physical compromise, alterations in customary social support, isolationism, psychosocial reorientation, and employment and insurance problems.

**Conclusions:** The continuation of a rehabilitation effort begun around the initial diagnosis of cancer would be instrumental in providing post-therapy evaluation and guidance needed by adult long-term survivors of cancer. Education, research, and support interventions need to be mobilized for this population of adults with a history of cancer.

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The promising news is that in 1988 more than 50% of all patients with cancer will survive long-term. Early in the 21st century, survival rates are expected to reach 66% (1). However, Izsak and Medalie (2) offered a word of caution as we rally around our successes:

Survival rates while justifiably important in themselves cover only a portion of the total problem. These rates do not relate to how the patient survives; at what cost to his physical functioning; how he adapted to his condition from a psychological point of view; and how he is fulfilling his roles, in his family, at work, among friends and in the wider society.

Whom are we describing when we depict long-term survivors; those persons associated with cancer cure?

It might be most useful to view the characteristics of long-term survivors in more generic terms. Mullan (3) explained, "There is no moment of cure but rather an evolution from the phase of extended survival into a period when the activity of the disease or the likelihood of its return is sufficiently small that the cancer can now be considered permanently arrested." Long-term survivors, then, can range from those living with persistent (but controlled) disease to those who are disease-free (Table 1).

Research on the psychosocial implications of surviving adult cancers has been compromised by methodologic problems. Many studies have focused on survivors of childhood and adolescent cancers but research addressing adult cancer survivorship is minimal. Little research exists that provides baseline pretreatment measurement of individual psychosocial responses with which to compare later findings (4-8); few of these studies extend into the long-term survival period. Cella and Tross (9) have described limitations in previous research. Heterogeneous subject pools have often been used with little or no control for important intervening variables of age, sex, primary site of cancer, type of treatment, and time since cancer. In addition, the relationship of disease to stage and psychological adjustment during survivorship has not been addressed.

We focus on the psychosocial aspects of surviving cancer and specifically delineate and describe the following related themes: fear of recurrence and death, relationships with the health care team, adjustment to physical compromise, alterations in customary social support, isolationism, psychosocial reorientation, and employment and insurance problems.

### Methods

The primary sources of identifying data for this review were MEDLINE and the *Index Medicus*. Exploration of secondary sources of information through bibliographic review uncovered additional articles and chapters from medical, nursing, social work, and legal literature. The literature search included the years 1970 to 1988.

Criteria for selection included literature that addressed a population with a primary diagnosis of an adult cancer and mainly focused on long-term survival without evidence of disease. The lack of prospective research in this area necessitated review of retrospective studies, case reports, and legal overviews. Of the 103 literature sources originally identified for review, 58 were selected to identify the psychosocial themes of long-term survival of adult cancers. Four reviewers from nursing and legal backgrounds agreed on the final literature selection.



**Table 1. Various Cancer Survival Trajectories**

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Live cancer-free for many years
Live long cancer-free but die rapidly of late recurrence
Live cancer-free (first cancer) but develop second primary cancer
Live with intermittent periods of active disease
Live with persistent disease
Live after expected death

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## Psychosocial Implications

### Fear of Recurrence and Death

Many survivors of cancer fear recurrence and death (9-14). Commenting on the importance and prominence of this fear, Northouse (14) noted that insufficient knowledge of when and if symptoms will recur affects the individual's overall sense of mastery and control over life. In a study of 60 male survivors of Hodgkin disease and 20 age-matched controls, Cella and Tross (9) found greater death anxiety in survivors within 2 years after therapy when compared with those coping with more protracted survival. This finding suggested a general lessening of death anxiety over time. Others (10, 12) have reported that fear of death is common during the treatment period and may persist years after therapy is completed.

Maher (12) indicated that reactions related to fear of recurrence ranged from worry and anger in the middle of the night to panic and thoughts of suicide. In comparing 104 cancer survivors 3 years after therapy with a matched sample of healthy controls, Schmale and coworkers (15) described a greater incidence of general health worries associated with recurrence and a sense of lower self-control in the survivor sample. Tross and colleagues (16) studied cancer-specific and general psychologic distress in survivors of testicular cancer and acute leukemia. The leukemia group had greater cancer-specific distress, chiefly related to persistent fears of recurrence. Metzger and associates (17) found borderline indicators of clinical depression in those cancer survivors exhibiting higher degrees of concern about recurrence; however, the persons in this sample were primarily in the first year after treatment. Derogatis (18) postulated that the psychosocial impact of cancer survivorship lessened with time. Hence, duration from diagnosis and completion of therapy should be considered when evaluating the psychosocial status of survivors. Fobair and Mages (19) noted a similar finding of diminished fear over time in their study of 35 long-term survivors interviewed 3 to 6 years after diagnosis.

Mullan (11) linked the fear of recurrence with unpredictable behavior by former patients. As a critical influencing factor, the fear of recurrence can either lead to hypochondriasis or physician avoidance. Waiting rooms engender stress in survivors as they wait for their follow-up examination and ponder similarities and differences between themselves and others with advanced disease sitting near them. For many survivors, contact with others with active disease reintensifies initial and distressful feelings of vulnerability and

lack of control, which are central to the theme of fear of cancer recurrence and death. Thus, these factors need to be considered by health care providers when evaluating long-term survivors.

### Relationship with the Treatment Team

Many patients anticipating the completion of therapy do so with ambivalence (12). Elation that the treatment is over is coupled with the anxiety of losing close contact and health status surveillance by the treatment team. This psychosocial distress can be translated into behavioral manifestations.

Gorzynski and Holland (20), in their general commentary on the psychosocial impact of testicular cancer in young men, noted behavioral changes toward the completion of therapy. The men talked more about fears concerning the cessation of therapy and had an increase in the number of phone calls to caregivers and more outpatient visits to seek attention for minor signs and symptoms which were potentially related to recurrence of cancer. One report (21) of agoraphobia, which developed after surviving cancer, described panic attacks stemming from fear of abandonment near the end of therapy. This phenomenon correlated with diminished contact with the health caregivers, in turn, triggering separation anxiety and fear of loss of control. Anger toward perceived inadequacies during the diagnosis and treatment phase may also predominate in survivors (12) (Table 1). Shanfield (22) described survivor bitterness over missed diagnoses, the ignoring of important complaints by physicians, and inadequate support during acute therapy as initiators of intense anger. Health care providers need to be aware of these changes and support the patient during his or her transition into the well role.

### Adjustment to Physical Compromise

The interrelationship of physical and psychosocial sequelae experienced by survivors cannot be emphasized enough (23). Disabilities related to the cancer or its therapies may remain a source of ongoing psychosocial distress during survivorship as physical impairment can generate anger and symptoms related to depression (10, 11, 24, 25, 27).

In their study of women cured of breast cancer, Woods and Earp (24) noted a relationship between the number of physical symptoms following mastectomy with the incidence and severity of depression. Fobair and associates (25) found energy loss to be correlated with both clinical depression and age in survivors of Hodgkin disease. Younger patients (under 34 years) had a return of energy within 1 year after therapy, whereas older patients required longer recovery periods. Cella and associates (26) also described persistent anticipatory nausea in 50% of survivors more than 2.5 years after completion of treatment. Wellish (27) commented that older survivors are more likely to experience physical compromise, such as exhaustion, during the early part of their illness and recovery, and less likely to have psychologic



problems. Conversely, younger survivors may initially experience more psychologic problems with less physical distress. Physical and psychosocial indicators of well-being during survivorship merit joint study.

### Alterations in Customary Social Support

Relationships with family, friends, colleagues, and sexual partners may be altered as a result of surviving cancer. Maher (12) suggested that the patient is most in need of interpersonal support after the completion of treatment but often finds it unavailable. Although we generally acknowledge the family's role in the overall adjustment of the patient to cancer, little research has addressed the psychosocial dynamics of family and other social relationships during survivorship (28).

The social stress associated with survivor re-entry into a "well role" is multifaceted. Many survivors perceive being treated differently by others; and relationships with family, friends, and colleagues must be re-adjusted. The intense outpouring of emotional support that the survivor experienced during the time of diagnosis and treatment may not be sustained once he or she no longer looks ill (12). Cella (28) noted that the cancer experience often strengthened the family unit, whereas friends or acquaintances with less personal investment avoided or abandoned the person with cancer. A sorting out process transpires between those friends and acquaintances who become closer and those who distance themselves from the survivor (28).

Although premorbid family style is an important assessment variable, even the most supportive family member is not immune to the psychologic stress associated with cancer (29). Woods and Earp (24) reported that survivors were aware they triggered emotional upset in family members by talking about their fears, which in turn promoted conversational isolationism. Within the family unit, some members may continue to react to the survivor in his or her sick role and may not be able to put the illness behind them (23). On the other hand, some survivors find it hard to give up the advantages of being a patient and return to the customary demands of life (19). Schmale and coworkers (15) found that both survivors and family members were cautious and less active even when the survivor had no obvious physical limitations a year after the cancer. Family members may also have exhausted their ability to give support during the survivor's active disease phase and feel the best thing to do is put the experience behind them (12). For the family, the task of being supportive while containing their own anticipatory fears about the survivor's condition is a difficult one.

Intimate relationships are also affected by the cancer experience. Fobair and colleagues (25), in contemplating the significant divorce rate in their sample of survivors of Hodgkin disease, postulated that marital stress which may accumulate during cancer therapy is often temporarily put aside during active treatment. This stress may produce serious disruption in the marriage after therapy is completed. In addition, with the

intensity of treatment-related stress in the past, the issue of infertility caused by treatments may gain new prominence for couples, especially those who are childless or unmarried (30, 31). Shover and Fife (31) suggested that the durability of the relationship depends more on the maturity and ability of the couples to resolve infertility issues rather than on their marital status.

Establishing the cause of sexually-related problems during long-term survival is a difficult task. Bergman and colleagues (32) reported that 18 of 24 men 2 years after orchiectomy or hormonal therapy had a greater tendency to report changes in their partner's response to them than those who received radiotherapy alone. These changes in partner's responses included decreased sexual openness, responsiveness, and emotional involvement. The investigators questioned the patients' own psychological response as a variable in this observation, particularly because sexual activity decreased after active therapy despite preserved functional abilities in most of the men. Impaired sexual functioning is associated with psychological and physical factors. Andersen (33) cautioned clinicians to distinguish between sexual difficulties of psychogenic or psychosocial origin from those physiologically related to the disease and its therapy. Symptom distress, functional impairment, and body image alterations represent major considerations in the many causes of sexual impairment. Additionally, depression, chronic anxiety, emotional concealment, and crisis over gender role identity are other emotional issues to consider (30). Andersen (33) also stressed that general circumstances that may cause sexual distress for any patient with cancer must be considered during survivorship. This distress may manifest itself as mood disturbance, changed health status, somatization, and reprioritization of current concerns.

Other aspects of long-term intimate relationships must also be considered. Schover and Fife (31) noted that even if the partner is willing to continue an existing relationship, some survivors reject this person in anticipation of being repudiated themselves. Reiker and colleagues (30) described changes in intimate relationships of survivors of testicular cancer. Most of the married men indicated that relationships with spouses were strengthened. Most men with lovers felt their relationships were strained. Schmale and coworkers (15), however, stated that cancer survivors without any significant relationship were most psychologically distressed. Northouse (14) noted a similar trend when she studied women who were in remission after breast cancer and found that those with fewer significant supportive relationships had higher fears of cancer recurrence. This finding may be partially explained by a reported sense of isolation and inability to share concerns with someone.

### Isolationism

The phenomenon of isolationism for cancer survivors has dual manifestations. Isolation by others implies an external cause, whereas self-isolationism indicates an



interpersonal source of conflict. Trillin (34) stated: "Cancer connects us to one another because having cancer is an embodiment of the existential paradox that we all experience. We feel we are immortal, yet we all know that we will die." This ambivalence from persons without a cancer history is closely tied to aversion of the survivor, avoidance of discussions about the person's cancer, and unpredictable behaviors (12). Shunning, a highly subjective phenomenon, is a pervasive one for cancer survivors (11). Work discrimination as a component of isolationism will be discussed in more detail later.

A concern about the degree of disclosure related to past cancer history can be of major significance to unmarried survivors. As new relationships are contemplated, the matter of sexuality often evokes yet another anxiety for this group of single persons (30, 31). In a pilot survey of 18 oncology nurses 4 years or more after therapy for cancer, Welch-McCaffrey (35) identified major stressors for the unmarried survivors as concern about sterility, explanations during courtship, and finding partners accepting of the cancer history once the diagnosis was disclosed. Cella and Tross (9) found that survivors were less inclined toward intimacy, suggesting a relation between the cancer experience and the ability to engage in warm, interpersonal relationships. The cancer history may set the survivor apart from peers by increasing the survivor's sense of alienation and social isolation.

#### Psychosocial Reorientation

The experience of having cancer produces tangible mental scars, characterized by a longstanding nature and a lack of psychopathology (11). These scars may represent a secondary benefit to having experienced cancer. Shanfield (22) described the experience of having had cancer as a permanent one, characterized by easy recall of the initial feelings and emotions associated with illness and the recovery period, a continuing concern about one's mortality, along with an enduring sense of vulnerability. Cella and Tross (9) also noted that even after definitive cure, survivors were less certain about living a long life and had anxiety and mood changes.

Although uncertainties persist for approximately 3 years after completion of therapy, there is generally no evidence that major psychopathology or severe psychosocial distress is a common correlate of cancer survivorship (15, 22, 23, 28, 36). Holland (37) suggests that individuals with a history of psychiatric disorders before a cancer diagnosis may experience more psychopathology after the diagnosis. Although major psychopathology is uncommon, survivors may have increased incidence of less serious emotional problems that tend to disrupt normal daily living patterns, thereby causing significant psychosocial distress (23). For example, the anniversary of the cancer diagnosis may trigger survivor reactions that parallel those present in the post-traumatic stress syndrome. These anniversary reactions include re-experiencing the diagnosis and nightmares or flashbacks about the cancer experi-

ence, all of which stimulate anxiety (9, 23, 28). These reactions, however, are generally not severe. Psychopathology should be considered though when the responses become recurrent, vivid, and overwhelming and cause withdrawal (23). Another emotional response that is minimally addressed in the literature (22) and may be disabling is survivor guilt. Seeing others with active disease, particularly while in the physician's waiting room, may cause individuals to reflect on their own experience and wonder why they and not others have survived.

Having experienced cancer often leads to a critical personal review of one's values and life priorities. Although associated with an intense crisis, cancer concurrently generates significant gains in life appreciation arising from the confrontation with mortality, sickness, and the struggle for health (9). Not only do survivors appear to become more satisfied about life as a whole, but they become more accepting of themselves and often find renewed interest in religion while they reflect on an improved quality of life for the present (30, 38). Mullan (3) termed this reorientation "life-rekindled." McCartney and Larson (39) stated that this value reassessment may in part counteract the stress related to physical disability associated with long-term survival. These secondary benefits associated with survivorship appear to overshadow the physical compromise that may accompany cure. However, this process may also account for the troubling confusion about periodic feelings of depression concurrent with an objective improvement in health status (12). Maher (12) also noted that resumption of life-oriented thought processes after the adjustment to the idea of death may be a difficult transition. For example, the ability to feel comfortable to make long-range plans can often take months to years.

#### Employment and Insurance Problems

##### *Employment Discrimination*

The work experiences of cancer survivors suggest that the reasons for less favorable outcome are rooted in mythology about cancer. Three predominant myths about cancer may impact on survivors' employment opportunities: Cancer is a death sentence; cancer is contagious; and cancer survivors are an unproductive drain on the economy (40, 41, 43). Many employers do not realize that more than 50% of all Americans diagnosed with cancer in 1988 will overcome their illness (42), that cancer is not contagious, and that cancer survivors have similar productivity rates as other workers (44).

Work-related problems may be classified into three general categories: dismissal, demotion, and reduction or elimination of work-related benefits; situations arising from coworkers' attitudes about cancer; and problems related to the survivors' attitudes about how they should be perceived by others, which may engender avoidance and alienation (45). Feldman (45) questioned 344 workers and youths with cancer histories about their employment and school problems before and after cancer. Fifty-four percent of white collar



workers, 84% of blue collar workers, and 25% of the employed youth reported job problems they directly attributed to cancer (45). Job rejection, one of the severest forms of discrimination, was experienced by 22% of the white collar workers, 13% of the blue collar workers, and 45% of the youth (45). In a study of 403 survivors of Hodgkin disease, Fobair and coworkers (25) also reported various job problems, including denial of insurance (11%), other benefits (6%), or a job offer (12%); termination of employment after therapy (6%), conflict with supervisors or coworkers (12%), and rejection by the military (8%). In a later study, Houts and colleagues (46) found that 39% of newly diagnosed persons with cancer reported at least one employment problem. In none of these studies, however, was comparison to a control group measured, so the significance of these findings remains to be clarified.

The work performance of survivors is not necessarily affected by their history of cancer. Wheatley and colleagues (44) surveyed Metropolitan Life Insurance employees and concluded that the work performance of employees who were treated for cancer differed little from that of others hired at the same age for similar assignments. Stone (47) surveyed 800 000 Bell Telephone employees and found that of 1351 employees with a cancer history, 77% returned to work after their diagnosis and treatment. Melette (48) later confirmed Stone's conclusion that of those survivors who had to leave work for treatment, most were able to return to their jobs. Crother's (43) summary of several studies concluded that 80% returned to work after diagnosis. Mor's (49) study of survivors employed at the time of diagnosis found that a higher percentage of white collar workers (78%) than blue collar workers (63%) remained in their jobs 12 months after diagnosis.

Although Greenleigh Associates (50) found that few of the 810 cancer patients they questioned reported special employment problems, some indicated that the net effect of having a cancer history was to lock them into their former jobs. Many stayed in undesirable jobs because they believed that changing jobs after having had cancer would result in lost hospital and medical insurance, pension rights, and other benefits.

In general, discrimination against cancer survivors who are qualified for jobs but are treated differently solely because of their cancer histories, violates most laws that prohibit employment discrimination against the handicapped. The Federal Rehabilitation Act of 1973 (51) prohibits discrimination by certain employers that receive federal funding. This law provides remedies to cancer survivors who are discriminated against either because they have a handicap or because their employers believe them to be handicapped. The Act applies only to a limited number of employers, such as most hospitals and universities and, therefore, does not provide a legal remedy to most cancer survivors.

Every state has a law that prohibits discrimination against the disabled. Most state laws cover both public and private employers. A few states, such as Califor-

nia, expressly prohibit discrimination based on a history of cancer. Other state laws protect individuals with real or perceived disabilities, and therefore, cover most cases of cancer-based discrimination.

#### *Problems with Insurance Coverage*

Because studies about cancer-related insurance problems vary dramatically in research methodology, the scope of insurance discrimination has yet to be clearly defined. The impact of barriers to insurability, however, is more easily assessed. Existing and anticipated insurance problems cause stress, anxiety about job security and economic stability, resistance to job change, lowered self-esteem, and anger over being denied insurance for statistically unsound reasons (52). Greenleigh Associates (50) concluded that much of the economic burden of cancer can be directly linked to the availability of adequate health insurance.

Most adults obtain health insurance through their employment (52), so many problems occur when employment is terminated or individual coverage is cancelled. Survivors who are not covered by group policies are the most vulnerable to insurance problems. Although cancer survivors have unique difficulties with all issues regarding insurance, securing and obtaining health benefits are the most problematic. Recent studies of cancer survivors have reported myriad barriers to insurance, including refusal of new applications, policy cancellations or reductions, higher premiums, waived or excluded pre-existing conditions, and extended waiting periods (52). Burton and Zones (53) estimated that almost 30% of all employable cancer survivors in California encounter barriers to insurance. Approximately 25% of the 940 cancer patients surveyed by the Mayo Clinic Rehabilitation Program reported insurance "discrimination" (52).

With the exception of a new Massachusetts law, neither states nor the federal government mandates a "legal right" to health insurance. Whether termination from a plan, denial of benefits under a plan, or refusal to issue insurance violates a law is determined by two factors: the applicable law and the terms of the policy. In most circumstances the applicable law will be state law. With the exception of COBRA (Consolidated Omnibus Budget Reconciliation Act of 1986) (54) and other federal laws (51, 55) that prohibit discrimination against the handicapped, the federal government does not regulate access to or terms of health insurance.

COBRA (54) is a federal law that requires employers to offer group medical coverage to employees and their dependents who previously would have lost their group coverage because of individual circumstances. Public and private employers who have more than 20 employees are required to provide for continuation of insurance coverage in cases where an employee resigns, is terminated, or works fewer hours. Coverage must extend to surviving, divorced, or separated spouses and to dependent children. Continued group coverage is provided for 18 months for the employee and for 36 months for spouses and dependents. Al-



though they have to pay for the continued coverage at rates that are usually more than group rates, the rate may not exceed 102% of the premium charged a similarly situated employee. Continuation of coverage must be offered regardless of any pre-existing conditions such as cancer.

Every state has an insurance commission or department that enforces state regulation of insurance companies. The commission determines what type of policies must be offered and when rates may be raised. State regulations cover all aspects of health insurance, including rates, policy conditions, termination or reinstatement of coverage, and the scope of coverage and benefits.

Some states have laws requiring the insurance industry to offer "high risk pools" for the medically uninsurable (56). Risk-sharing pools are designed to ensure that all individuals have the opportunity to purchase adequate health insurance regardless of pre-existing conditions such as cancer. State laws require major insurers to participate in the plan and share the risks and expense. Risk pools usually provide a comprehensive package of benefits with a choice of deductibles. Although the premiums are higher than individual insurance, most states impose a limit on the amount that can be charged.

### Recommendations

This overview of psychosocial aspects of long-term cancer survival gives direction for important interventions that require attention. The needs of survivors of adult cancers are newly recognized so we have little history and experience to guide intervention planning. Critical action, however, is required particularly in the areas of education, research, and what Mullan (11) calls "creating community", or support.

### Education

Forewarning and problem-solving in the context of education assists many patients with cancer and their families to cope better in the diagnostic and treatment phases of illness. We have not yet identified anticipatory education to be effective in the survival trajectory; however, survivors themselves reported that education was significantly important for their well-being (11, 25). Fobair and colleagues (25) found that patients wanted to be informed of the potential disruptions in their lives before experiencing them. Thus, the investigators advocated sharing the following information with survivors: energy loss may be a problem for 1 year after therapy and perhaps longer for older survivors; marital stress is common; and employers often require consultation to explain the survivor's work-related limitations imposed by the cancer. Mullan (11) stressed that the fear of cancer recurrence is common and that education about this fear is necessary. In addition, survivors need information to cope with the

psychosocial stress generated by significant physical disability and the associated changes.

The rationale for follow-up and the specifics of an individual plan for ongoing education and evaluation should be based on the patient's age, treatment-related complications, type of cancer and its metastatic potential, and any special needs (11). An unknown factor is how sharing the specific symptoms associated with a particular cancer's recurrence affects survivor anxiety. Educational support in the treatment phase provides a smooth transition to survivorship and should be provided by all health professionals.

### Support Groups

The community aspect of psychosocial intervention centers around the development of formal and informal survivor support groups and survivor reunions. These groups are only now beginning to be associated with cancer care. How they will influence the reduction of stress associated with the central themes of death and loss is yet to be identified. Support associated with re-entry into the work force, much like what we provide at school for children with cancer, needs to be evaluated. The benefits of individual, group, peer, and marital counseling also remains to be seen. Yet it does appear that ongoing support may help survivors in adapting to the psychosocial stress of survivorship.

### Research

Cancer survivors are a large and rapidly growing group about which relatively little systematic psychosocial information has been obtained (28). Hence, a number of research questions and issues need to be addressed: Would a staging system (3) for the survival period assist clinicians in addressing the specific needs of patients and former patients at various points of their experience? How is survival affected (17) by the developmental stage of life at which cancer occurs? Another area that must be addressed is defining the mediators of stress for long-term survivors. For example, the efficacy of various self-care strategies used throughout survival might confirm the advantages of exercise, nutritional support, biofeedback, and stress reduction. In the face of uncertainty, attempts to increase personal control are of significant benefit to many (57).

Other questions arise as to what types of educational interventions enhance adaptation throughout the continuum of long-term survival, and how time since diagnosis, severity of treatment, and the relation of physical compromise with psychosocial distress affect survival?

The pattern of survivorship is yet another important consideration for we cannot assume that the survival trajectory is the same for all (Table 1). For example, Scott and coworkers (57) described a man with repeated remissions whose life pattern consisted of multiple reprieves from death, followed by the challenge of living once again. These authors noted that when life's certainty is interrupted numerous times, ambigu-



**Table 2. Resources and Interventions for Employment and Insurance Problems Related to Cancer Survivors**

Category	Employment	Insurance
Problems	Dismissals Denial of new jobs	Inability to secure any health insurance Difficulty in securing benefits under an existing plan
	Demotions Undesirable transfers	Loss of insurance coverage for survivor dependents Job-lock because of fear of losing insurance benefits
Resources	Isolation and hostility in workplace Mandatory medical examination unrelated to job duties	High cost of individual policy premiums
	State and Federal antidiscrimination laws Disability and employment law attorneys	State insurance departments Professional and service organizations for group insurance plans
Interventions	Cancer survivor organizations Other physicians, oncology nurses, social workers	Cancer survivor organizations Other physicians, oncology nurses, social workers
	Educate survivors about employment rights	Assist survivors in obtaining health insurance policies
	Provide written statements to employer regarding patient's ability to perform job	Support development of high-risk pools
	Assist survivors with self-assessment of physical abilities	Encourage enforcement of health insurance laws (for example, COBRA)
	Help survivors locate community, state, and federal resources to meet employment needs	Help survivors locate resources to meet insurance needs
	Develop community-based survivor programs staffed with personnel who can address employment problems	Develop community-based cancer survivor programs with staff trained to address insurance problems
	Support efforts to expand legal rights of survivors in the work place	Support efforts to expand legal rights of survivors related to insurance
	Update other physicians about employment problems and needs of survivors	Update other physicians about insurance problems and needs of survivors

ity increases and acute but fairly long-lasting high levels of anxiety are generated.

Other important areas include the relation of pre-morbid coping style with emotional responses during survival, how attitudes and behaviors of health professionals affect the chronic anxiety associated with long-term survival, and the entire spectrum of the family's response to long-term survival.

No easy remedies exist to resolve the employment and insurance problems experienced by cancer survivors. At least three areas must be explored to combat employment discrimination. First, public and professional education is needed to dispel the cancer mythology at the root of much discrimination against persons with cancer (43, 58). In addition, advocacy steps should be taken to develop appropriate remedies to individual problems. Finally, cancer survivors should be encouraged to enforce their rights to equal job opportunities under current federal and state laws.

In order to eliminate barriers to health insurance, updated economic assessments on the financial costs of cancer treatment and long-term survival are urgently needed, especially because current statistics on cancer survival rates are easily obtainable (52). In addition, carefully structured prospective psychosocial studies with sufficient control populations are required to assess the scope of cancer based insurance problems. With accurate national data, concrete health insurance alternatives and legal rights can be tailored to remedy the failure of our current health care system to provide adequate insurance benefits to all cancer survivors. Specific resources and interventions for both employment and insurance problems are outlined in Table 2.

## Conclusion

Mullan (3) stated: "The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly, but also to map the middle ground of survivorship and minimize its medical and social hazards." The general rehabilitation focus that is so prominent, for example, in cardiac care, should be adopted for cancer care. A distinctly different body of health professionals is not required to undertake the task of support during survivorship. Rather, an extension of support from those who are treatment-focused into the phase of post-therapy evaluation and guidance is needed. Seventy-three percent of Fobair's (25) sample of 403 survivors averaging 9 years since completion of therapy experienced at least one psychosocial problem. The generalizability of these findings suggests that adult cancer survivorship is associated with more problems than generally expected. Hence, multiple interventions in the psychosocial realm during long-term cancer survival are needed.

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