Mental Illness Stigma as a Barrier to Psychosocial Services for Cancer Patients

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Psychosocial services, stigma, cancer

Abstract
Empirically validated psychosocial interventions have been shown to improve adjustment and coping among cancer patients. Therefore, an emerging standard of practice is to integrate supportive services for cancer patients into the medical management of the disease. However, unanticipated barriers may negatively influence receptivity to psychosocial services. For example, among the general population, two-thirds of individuals in need of psychiatric services do not receive them. Numerous barriers have been reported that interfere with receipt of mental health services among members of the general population. In addition to access issues, stigma associated with mental illness and its treatment represents a significant barrier to care. Stigma associated with mental illness and mental health services use is an under-researched barrier to the effective management of the psychosocial sequelae of a cancer diagnosis and treatment. This article reviews the relevant literature on mental health stigma and makes recommendations for increasing access to psychosocial services for cancer patients and their families. (JNCNN 2003;1:375-379)

Cancer is the second leading cause of death, killing more than a half a million Americans each year. During the past decade, overall cancer incidence and death rates have declined steadily. Research suggests that 90% of patients with early-stage breast cancer and 100% of patients with localized prostate carcinoma will survive their illness. Increased diagnostic screening, scientific advancements, and lifestyle changes have been proposed as the primary factors associated with improved cancer outcomes. Together, these advances have resulted in the increasingly large numbers of individuals who are disease free and in the extension of survival in individuals with metastatic disease.

Psychological Reactions to the Diagnosis
As survival rates improve for breast and other types of cancers, emphasis is shifting toward improving not only the overall quantity of life, but also quality of life (QOL). Emotional well-being is a significant QOL concern for individuals with a cancer diagnosis. Research indicates that psychological disturbance among cancer patients is common, with anxiety and depression being the most prevalent emotional problems. Risk factors predictive of poor post-diagnostic coping and QOL include younger age at time of diagnosis, multiple life stressors, low sense of control, lack of social support, history of depression, and a hopeless or helpless outlook.

Psychosocial interventions have shown efficacy in reducing depression, anxiety, and functional impairment, and improving overall QOL among individuals with cancer. Typically, three types of interventions are available: 1) educational techniques to improve the understanding of cancer and its treatment; 2) behavioral techniques to reduce specific cancer-related symptoms; and 3) individual and group psychotherapy or support groups. Additionally, researchers are examining the use and benefits of complementary and alternative therapies as well as the role of spirituality in adjustment to illness.

Use of Psychosocial Services
Given the known benefits of psychosocial interventions, what proportion of cancer patients are using services? The extant literature suggests that 25% to 67% of cancer patients participate in psychosocial supportive services. However, variations in use may occur based on characteristics of the sample and type of support program being of-
ferred. For example, in a recent study of breast, prostate, and colorectal cancer patients (Matheus AK, Manfredi C, and Johnson T, unpublished data) only 19% of the overall sample (N = 430) reported any use of psychosocial services. Of those individuals reporting any use of services, 15% reported participating in a cancer support group and 6% in individual psychotherapy.

It is important to note that the mean age for the overall sample was 60 years of age. Previous research suggests that older adults are less likely to report mental health service use. However, interesting differences were observed in the rates of seeking psychosocial services based on cancer site. Breast cancer patients (27%) were significantly more likely than either prostate (13%) or colorectal cancer patients (9%) to have sought assistance. It is not clear if these findings reflect a gender difference in help seeking or the greater availability of supportive services for breast cancer patients. Further research is needed to identify facilitators and barriers to receipt of psychosocial services for cancer patients.

**Barriers to Care**

Preliminary findings suggest that barriers to the provision of psychosocial services to cancer patients are multidimensional and stem from low referral rates by medical providers, fragmentation of care, and low acceptance by patients. Although some barriers may be unique to the provision of psychosocial services, barriers to increasing support for individuals with cancer must also be understood against the larger backdrop of barriers to receipt of mental health services in general. These barriers include the cost of mental health services; fragmented organization of services; cultural beliefs and attitudes regarding mental illness and treatment seeking; and the lack of cultural or language proficiency of mental health providers. Further, a significant but poorly understood barrier relates to stigma associated with mental illness and mental health services use. Among nonmedical populations, discrimination and community misconceptions remain among the most significant barriers to people with a mental health problem accessing needed services. Indeed, in a 1999 report on mental health, the Surgeon General identified stigma as a key barrier to obtaining treatment for persons with mental illness. Stigma associated with psychological treatment also is recognized as a factor in the availability and use of psychological services among cancer patients.

**Stigma as a Barrier to Care**

What is stigma? Stigma is defined as any "discrediting attribute that disqualifies one from full social acceptance." Common stigmatizing attitudes associated with mental illness expressed by the general population relate to fear and exclusion ("persons with mental illness are dangerous and should be kept out of most communities"), authoritarianism ("persons with mental illness are irresponsible and as a consequence, their life decisions should be made by others"), and benevolence ("persons with mental illness are childlike and need to be cared for"). Surveys of people with mental illness have yielded several findings: the majority report feeling stigmatized, expect to be treated poorly by the public, are treated as less competent by others once their illness is known, and suffer low self-esteem because of internalized stigma. Individuals with cancer may fear the compounded stigma that may result from having cancer and being labeled as requiring psychological treatment.

Stigma has been shown to affect people with mental illness in several important ways. The first is externally through rejection by friends, relatives, and employers. The second is internally in the form of aggregated feelings of rejection, shame, and depression within the person. Finally, state laws and social policies have been shown to institutionalize prejudice and discrimination. These various forms of stigma affect individuals with mental illness or mental health problems by reducing their treatment seeking and overall well-being.

Nationwide epidemiologic studies suggest that mental illnesses affect one of five Americans at some point in our lives. However, only one-third of Americans with a mental health problem get needed care. Unmet mental health needs may be an even larger problem among ethnic and racial minorities. A recent report by the US Surgeon General concluded that members of other ethnic groups may experience a greater burden from unmet mental health needs than Caucasians because of the combined influences of reduced access to care, lower quality of services received, and reduced voluntary use of mental health services. The report also pointed to the importance of understanding the role of cultural and social factors in the development, experience, treatment, and recovery from mental health problems. Understanding factors associated with attitudes toward and use of mental health services is an impor-
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Addressing Barriers

What can be done to reduce stigma and other barriers and improve the receipt of psychosocial services for cancer patients? The Surgeon General's report on overcoming barriers to mental health treatment in the general population can be directly applied to the population of cancer patients. As outlined in Table 1, strategies aimed at increasing use of needed mental health services include increasing public awareness of effective treatments, increasing access to care, ensuring delivery of state-of-the-art treatment, reducing stigma, and continuing to build a science base.

The first step to addressing barriers relates to improving public awareness about the effectiveness and availability of psychosocial services. A meta-analysis examining well-designed psychosocial interventions showed that there are a number of effective treatments that successfully reduce the impact severity of diagnosis and treatment and enhance overall quality of life. However, as we mentioned earlier, a substantial proportion of cancer patients may not be aware of available services; may not understand how psychosocial treatment can improve their adjustment and ability to cope with their illness; or may perceive mental health treatments to be of low effectiveness. Improving attitudes by increasing knowledge and understanding about psychosocial adjustment in both providers and patients will be a necessary component of reducing barriers to treatment.

A second strategy is to increase access to mental health services. Advocating for parity between mental health coverage and other health coverage is an effective way to decrease the number of people who do not receive necessary treatments. However, increased coverage is only one limiting factor to sufficient access. Other components include facilitation of entry into treatment, availability of a wide range of services in both the hospital setting and the community, reducing financial barriers to treatment, and eliminating institutional barriers to treatment. In the medical setting, increasing access to care will necessarily require increasing awareness of need and acceptance of services by medical providers, appropriate referrals from treatment providers, and integration of services within a traditional medical systems framework.

Table 1 Strategies to Reduce Stigma Associated with Psychosocial Services

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<td>1. Improve public awareness of effective treatment</td>
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<td>Appropriate dissemination of treatment findings to public, patients, and providers</td>
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<td>2. Increase access to care</td>
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<td></td>
<td>Facilitate entry into treatment</td>
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<td>Provide a wide range of services in the hospital and community settings</td>
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<td>Reduce financial barriers to treatment</td>
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<td>Reduce institutional barriers to treatment</td>
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<td>3. Ensure delivery of state-of-the-art treatment</td>
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<td>Use of evidence-based treatments</td>
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<td>Improve the cultural competency of mental health providers</td>
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<td>Improve the efficiency of providers in addressing the specific psychosocial needs of cancer patients</td>
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<td>4. Reduce stigma</td>
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<td>Incorporate mental health professional into a multidisciplinary care team</td>
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<td>Educate providers about the role of mental health providers in medical settings</td>
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<td>Conduct a psychosocial assessment of all patients to identify needs and to reduce the perceived stigma of being &quot;singed-out.&quot;</td>
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<td>Adopt a psychoeducational approach to treatment</td>
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<td>Use of appropriate language and framing of problems</td>
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<td>5. Continue to build science base</td>
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<td>Continue to identify the psychosocial needs of cancer patients beyond breast cancer</td>
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<td></td>
<td>Identify facilitators and additional barriers to specific psychosocial services</td>
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<td>Identify what treatments are most effective and for which patients</td>
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Providing high-quality care is a third component of increasing access to treatment for cancer patients. Quality care encompasses the use of evidence-based and efficacious treatment as well as the competency of providers in delivering services to diverse groups of patients. Cultural competency is critical to providing quality care given the relationship between culture and many aspects of mental health, including the prob-
lems encountered, attitudes about mental health, symptom manifestation, expression of emotions, availability of support, and willingness of individuals to seek treatment. In addition to understanding the unique needs of cancer patients and their families, providers must understand the influence of culture on individual behaviors to appropriately provide services and increase treatment acceptance.

For example, in addition to access and system barriers to treatment, studies examining attitudes toward mental illness and mental health services suggest that cultural values and beliefs about mental illness, mental health services, and culturally consistent strategies for coping with stress influence mental health services use. Compared with Caucasians, African Americans report higher levels of mistrust, negative attitudes, and fear of being hospitalized associated with use of professional mental health services. Studies suggest that some minority group members may view receipt of mental health services as more socially stigmatizing than Caucasians. By understanding cultural variations in service use and coping responses, mental health professionals can implement more effective strategies to improve care for all cancer patients.

Stigma reduction is a fourth strategy that has been endorsed for increasing access to treatment. A primary strategy for reducing stigma associated with psychosocial service is to incorporate mental health professionals into a multidisciplinary cancer care teams. The role of the mental health providers should be to conduct a brief psychosocial assessment of all patients to identify needs and reduce the perceived stigma of being “singled-out” as being unable to effectively cope with one’s illness and to provide services for patients with identified needs. It should be noted that most cancer patients will not be experiencing severe mental health problems. Therefore, providers should adopt a psychoeducational approach to treatment for this population. Psychoeducational services are more readily accepted by most patients than psychotherapy, per se, because of the focus on increasing knowledge about known challenges, treatment strategies, resources, and providing more intensive services if needed. Furthermore, a psychoeducational approach may help to normalize the patient’s experience by focusing on mood disturbance as a common experience to the acute and chronic stressors associated with cancer diagnosis and treatment.

A final strategy relates to continued empirical research in providing appropriate services for cancer patients and their families across the entire continuum of care. Members of our group conducted an evaluation of psychosocial services provided to patients referred for assessment in a genetic risk assessment clinic. Over one hundred (N = 102) patients received genetic risk assessment services in the context of a comprehensive medical clinic that included a medical evaluation, genetic risk assessment, and mental health services. An evaluation was conducted to evaluate satisfaction with services and to identify factors associated with increased interest in receiving follow-up services. Seventy percent of respondents felt that it was useful to incorporate provision of mental health services into standard medical services. In addition, 41% of the sample reported interest in a follow-up appointment. Interest in receipt of additional services was associated with higher levels of cancer worry, lower self-reported emotional functioning in the past 12 months, and higher scores on a standardized measure of depression and general distress. Identified factors that facilitate the use of psychosocial services included: counselors with specific cancer training; services covered by insurance; services available for family and partners; and treatment that was brief and focused.

Conclusions
Meeting the psychosocial needs of individuals with cancer will require a two-pronged approach: continuing to identify the psychosocial needs of cancer patients and investigating the most effective methods of addressing them. In part, addressing the needs of cancer patients may require combating the barriers to mental health care that exist in the larger society, namely stigma. Results have shown that relatively brief education programs can lead to significantly improved attitudes about mental illness. Future research needs to more directly examine the impact of public stigma on acceptance of psychosocial services by cancer patients and determine the most efficacious strategies for reducing the negative impact of stigma.

References

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