Promoting evidence-based psychosocial care for cancer patients

Paul B. Jacobsen*
Department of Health Outcomes and Behavior, Moffitt Cancer Center and Research Institute, Tampa, FL, USA

Abstract
With numerous studies demonstrating that psychosocial care reduces distress and improves quality of life, practitioners have an obligation to treat cancer patients in a manner consistent with this evidence. Although the rationale is straightforward, major challenges exist in achieving the goal of translating research into clinical practice. One challenge has been the nature of the evidence, with many studies of psychosocial interventions characterized by poor methodological quality, absence of eligibility criteria specifying heightened distress, and minimal consideration of dissemination potential. A second challenge has been to make practitioners aware of relevant evidence. Targeted efforts at dissemination, such as the issuance of clinical practice guidelines and evidence-based recommendations and the distribution of intervention materials via the Internet, appear to be more effective than passive efforts in providing practitioners with useful information. Perhaps the most challenging aspect has been to persuade practitioners to change how they practice. One approach currently under development would allow practitioners and health-care organizations to perform self-evaluations of the quality of their psychosocial care based on review of medical records. Feedback showing quality of care to be less than optimal is likely to motivate change, especially if the quality indicators assessed are considered to be important and reliable and point to specific actions that can be taken. The use of evidence to promote changes in clinical practice represents one of the major ways in which the field of psycho-oncology can fully realize its potential to positively affect the lives of people with cancer.

Keywords: cancer; evidence-based medicine; psycho-oncology; quality of care

I am honored to be the 2008 recipient of the Bernard H. Fox Memorial Award. Bernie was widely regarded as the ‘conscience’ of psycho-oncology because of his dedication to ensuring that research in our field met the highest standards of scientific integrity [1]. I first met him while I was a post-doctoral fellow in the 1980s, during one of his many visits to Memorial Sloan-Kettering Cancer Center. Over the years that followed, he would call me on several occasions with questions about various studies he had read, including some of my own. These conversations would invariably turn into, what was for me, an advanced tutorial on research methodology and its application to psycho-oncology. I learned a great deal from Bernie about standards of scientific evidence and the features that characterize well-designed studies. Consistent with Bernie’s efforts to establish psycho-oncology on a sound scientific footing, I have chosen to speak to you today about promoting evidence-based psychosocial care for cancer patients.

Efforts to promote evidence-based psychosocial care for cancer patients can be viewed as part of a larger effort to promote ‘evidence-based medicine’. The field of evidence-based medicine arose, in part, to address problems with the quality of health care. Numerous reports and publications have shown that many patients fail to receive the care shown in clinical research to be effective for their disease or condition [2–5]. An important example is a widely cited study, which found that medical patients typically received only 55% of the care that would be recommended for them based on their history and health status [5].

Similar to many frequently used terms, evidence-based medicine has been defined in different ways. According to its major proponents, the practice of evidence-based medicine involves integrating individual clinical experience with the best available external clinical evidence from systematic research [6]. Delivery of health care based only on clinical experience is viewed as running the risk of becoming rapidly out of date to the detriment of patients [6]. On the other hand, without the benefit of clinical experience, the delivery of health care is viewed as running the risk of becoming tyrannized...
Consideration of the quality of psychosocial care for cancer patients is a timely topic. In 2007, the US Institute of Medicine (IOM) released a report titled, ‘Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs’ [7]. One of the report’s major conclusions is that, despite good evidence for the effectiveness of services in meeting patients’ psychosocial needs, cancer care often fails to address these needs [7]. The reasons for this failure are many and include the tendency of oncology care providers to underestimate distress in patients [8] and to not link patients to appropriate services when needs are identified [9]. To address these problems, the report recommends that provision of appropriate psychosocial services be adopted as a standard of quality cancer care [7]. The report also identifies a model for the effective delivery of psychosocial services. According to the model, for effective delivery of care to occur, processes need to be in place to: (1) identify psychosocial needs; (2) link patients and families to needed psychosocial services; (3) support patients and families in managing the illness; (4) coordinate psychosocial and biomedical care; and (5) follow up on care delivery to monitor the effectiveness of services and make modifications if needed [7].

These recommendations are comparable to those contained in the Cancer Service Guidance on Supportive and Palliative Care developed by the UK National Institute for Clinical Excellence (NICE) and in the Clinical Practice Guidelines for the Management of Distress developed by the US National Comprehensive Cancer Network (NCCN). Similar to the IOM report [7], the NICE report concludes that there are wide variations in the quality of supportive and palliative care, with many cancer patients not receiving services that could benefit them [10]. The bulk of the document consists of a series of recommendations and descriptions of various service models designed to ensure that patients and their families receive support and care to help them cope with cancer and its treatment at all stages. For example, the section focusing on psychological support recommends, similar to the IOM report [7], that providers should ensure that all patients undergo systematic psychological assessment at key points in their illness and have access to appropriate psychological support [10]. The report then identifies a four-level model of increasingly intensive psychological assessment and intervention that could be used to achieve the recommendation [10].

The NCCN guidelines, first issued in 1999 [11] and updated annually, were developed based on the recognized need for better management of distress and with the intent of promoting best practices for the psychosocial care of cancer patients. Although too detailed to be fully summarized here, the NCCN guidelines are presented in the form of clinical pathways that describe recommended procedures for evaluating patients and recommended uses of psychological, psychiatric, social work, and pastoral care services to treat a wide range of problems. Similar to the IOM report [7], the NCCN guidelines recommend that all patients be routinely screened to identify the level and source of their distress. The specific services and resources subsequently recommended are designed to be appropriate to the nature and severity of the problems identified through the initial screening and further evaluation [11].

By specifying standards of care and identifying clinical pathways, the IOM and NICE reports and the NCCN guidelines have the potential to improve the quality of psychosocial care received by cancer patients. However, each of these initiatives has limitations with regard to the use of evidence. Most of the recommendations offered in the NCCN guidelines are identified as being based on lower-level evidence that includes clinical experience [11]. This situation is true even though higher-level evidence could be cited in several instances. For example, the NCCN guidelines recommend that psychotherapy be considered in the management of anxiety and depression [11]. Although several psychosocial interventions have been found to be effective against anxiety and depression in RCTs with cancer patients [12], these research-supported interventions are not identified in the guidelines. With regard to the NICE report, the authors acknowledge that there is no formal evidence of the benefits of implementing the recommended four-level model of psychological assessment and intervention. With regard to the IOM report, it is noteworthy that there is no explicit statement in the standards of care that the psychosocial care provided to cancer patients should be evidence-based [7].
Use of evidence to guide clinical practice in psycho-oncology

The current status of recommendations for psychosocial care shows how much more needs to be done to promote the translation of research findings into everyday clinical practice. Part of the problem reflects limitations in the existing evidence base in psycho-oncology. Consider, for example, evidence on the efficacy of psychosocial interventions against anxiety and depression in cancer patients. Over 60 RCTs have been conducted in which the effects of psychosocial interventions on anxiety or depression in adult cancer patients have been evaluated and several systematic reviews and meta-analyses have been conducted summarizing the results of these studies [12–16]. A recent summary of these reviews and meta-analyses identified three major weaknesses in this evidence base [17].

First, the research is characterized by inconsistent findings. One systematic review examined whether at least 75% of the trials evaluating a specific strategy yielded statistically significant positive results [13]. Only one strategy was found to have met this criterion for anxiety and none met it for depression [13]. This lack of consistency can be attributed, in part, to differences across studies evaluating the same intervention strategy in the demographic, disease, and treatment characteristics of the samples recruited, the number and timing of the outcome assessments performed, and the outcome measures used. In addition, there appears to be considerable variation across studies in the number and content of sessions for interventions that share the same name (e.g. relaxation training).

The quality of the studies is a second major weakness. Inadequate reporting of study methodology appears to be a major problem. One review of this literature found that only 3% of trials provided sufficient information to permit evaluation of 10 indicators of study quality [13]. However, problems are also evident when study methodology is adequately described. For example, the majority of studies conducted in the 1990s failed to account for patients lost to follow up in the outcome analyses that were performed [13].

The general lack of research on patients experiencing clinically significant levels of distress is a third major weakness. One review found that only 5% of studies limited eligibility to patients experiencing some degree of anxiety, depression, or psychological distress [12]. Based on the reported prevalence rates in oncology settings [18,19], the average patients in most intervention studies were likely to be experiencing low levels of anxiety and depression at the time they were recruited. In addition to limiting the statistical power to detect intervention effects, the lack of eligibility criteria based on current levels of distress raises questions about whether the findings are generalizable to patients experiencing clinically significant symptomatology. This issue is important since clinical practice guidelines, such as those developed by NCCN [11], recommend the use of psychosocial interventions specifically for patients experiencing heightened distress.

Another part of the problem in promoting the translation of research findings into clinical practice involves the way in which the evidence base in psycho-oncology is generally used. Systematic reviews and meta-analyses of the research literature often focus only on providing an overall conclusion regarding the efficacy of psychosocial interventions for cancer patients. Depending on how the evidence is weighed, the conclusions arrived at may be quite different. For example, two recent reviews that examined many of the same publications reached very different conclusions about the overall effectiveness of psychosocial interventions for cancer patients. While one review [20] concluded that, ‘the preponderance of evidence furnished by these systematic reviews, particularly that gleaned from meta-analyses, suggests that psychological interventions are effective in managing distress’, the other review [21] concluded that, ‘our review of reviews, particularly the more systematic reviews, provides no compelling evidence of broadly effective psychological interventions for reducing a wide range of distress outcomes in cancer patients’.

Rather than attempt to reach an overall conclusion about the efficacy of psychosocial interventions, it may be more useful for efforts to translate research into practice to use the research findings to derive specific evidence-based recommendations for the psychosocial care of cancer patients. One approach others and I have worked to develop involves summarizing the literature in terms of the number of RCTs that yielded positive results for a particular endpoint (e.g. anxiety or depression) based on intervention type and patient disease or treatment status [17]. Providing this information to practitioners can serve several useful purposes. First, it readily identifies when in the disease course or at what point in the treatment process a specific intervention strategy has been shown to be effective. Second, the number of unique citations next to each listing indicates the strength of the evidence for that application of an intervention strategy. Finally, the citations themselves identify publications that provide information about the content and delivery of an intervention and the methodology that was used to evaluate it.

A variant of this approach was used by the National Breast Cancer Centre and the National Cancer Control Initiative in Australia to develop the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer [22]. These guidelines are also presented in the form of a series
of recommendations, accompanied by the identification of the levels and sources of research support. An assumption underlying these guidelines is that evidence collected from other populations is generalizable to cancer patients. That is, some of the evidence cited to support recommendations comes from systematic reviews and randomized trials conducted on populations other than cancer patients.

**Promoting the use of evidence-supported psychosocial interventions**

Current efforts to promote the use of evidence-supported interventions in psycho-oncology consist largely of diffusion of information via publication of individual research studies and dissemination of information via publication of systematic reviews and meta-analyses. As described earlier in this article, there have also been limited efforts by individuals and organizations to disseminate information about interventions via evidence-based recommendations [17,22]. Experience suggests that these passive efforts at diffusion and dissemination of information are likely to have only a limited impact on everyday clinical practice [23].

A project initiated by the US National Cancer Institute and several other US governmental bodies represents an important step forward in efforts to promote implementation of evidence-supported interventions for psychosocial care of cancer patients. The project, Cancer Control Plan, Link, Act, Network with Evidence-based Tools (PLA-NET), consists of a web site (www.cancercontrol-planet.cancer.gov) that provides a link to a list of interventions relevant to the prevention, detection, and control of cancer. To be listed, an intervention must meet several criteria including having been developed with funding from a peer-reviewed research grant and having been evaluated in a study published in a peer-reviewed journal. In addition to describing an intervention, the web site provides ratings by peer reviewers of its dissemination capability, the strength of the research evidence supporting its efficacy, and its gender, cultural, and age appropriateness. There are also links that provide information about how to obtain the training manuals and other materials that may be necessary to deliver the intervention. Beyond this, the web site offers a web-based course designed to promote implementation by providing instruction on how to adapt a research-tested intervention program to a local community context.

Although Cancer Control PLANET and similar resources can facilitate the dissemination and implementation of existing research-tested interventions, several impediments to implementation remain. One major impediment to efforts to promote greater implementation of evidence-based psychosocial care of distress in cancer patients is the general lack of research on integrated models of care delivery. As noted previously, the NCCN guidelines describe a model of care that features screening to identify patients’ level and source of distress, selection and use of appropriate intervention strategies that may include psychotherapy and pharmacotherapy, and follow-up evaluations of patients’ status [11]. Contrast this approach with most RCTs of interventions for distress in cancer patients. These trials have generally accepted participants regardless of their level of distress and have generally focused on psychosocial rather than pharmacological or combined modality interventions [12]. Consequently, most of the evidence base in psycho-oncology has little bearing on the NCCN model of care, a model that probably reflects how psychosocial care is organized in many oncology settings.

Psycho-oncology investigators seeking examples of research on integrated models of care delivery should consider studies evaluating the collaborative care of depression in primary-care settings. The specific elements may vary from study to study; however, most collaborative care interventions share these basic features: depression screening to identify cases; use of evidenced-based protocols for treatment of depression; structured collaborations between primary-care providers and mental health specialists; and active monitoring of adherence to treatment and outcomes [24]. A recent meta-analysis identified 37 randomized studies that have evaluated collaborative care for depression among patients seen in primary-care settings [25]. Overall, findings indicated that collaborative care yielded significantly better outcomes on standardized measures of depression at six months, with significant effects still present at five years in those studies that included a long-term follow-up assessment. The evidence for the efficacy of this intervention is considered to be sufficiently strong as to raise questions about whether further trials of collaborative care in the primary-care setting are necessary [24,25].

Even though this model of care is of considerable relevance to oncology, it has received limited research attention to date. A search of the literature identified only two studies in which it has been studied with cancer patients. In the first study, described as a pilot project, 55 low-income Latina patients with breast or cervical cancer found to have comorbid depression through screening in an oncology clinic were randomly assigned to usual care or a collaborative care intervention [26]. The intervention included initial and follow-up sessions with a master’s level social worker trained to provide problem-solving therapy, support for antidepressant medication adherence, and assistance with systems navigation. Findings showed
significantly better outcomes for the collaborative care group. Specifically, 37% of women in the collaborative care condition versus only 12% of women in the control condition displayed a clinically significant reduction in depressive symptomatology by the four-month follow-up assessment.

In the other study, 200 cancer patients being treated at a regional center, who were found to have major depressive disorder through screening, were randomly assigned to usual care or usual care plus a collaborative care intervention [27]. The intervention consisted of up to 10 sessions with a cancer nurse who provided education about depression and its treatment (including antidepressant medication) and problem-solving therapy to overcome feelings of helplessness. In addition, the nurse communicated with each patient’s oncologist and primary-care doctor about management of major depressive disorder. Findings showed significantly lower scores on a measure of depressive symptomatology three months post-randomization for patients who received the collaborative care intervention. These differences are reflected in the percentages of usual care patients (45%) versus collaborative care patients (68%) whose major depressive disorder had remitted in the three-month period. The beneficial effects of collaborative care observed at three months were still evident at 6-month and 12-month follow-up assessments.

These two studies provide strong evidence that an integrated model of care delivery, which includes routine screening and care delivered according to a standardized protocol, can improve the management of depression in cancer patients beyond usual care. It is noteworthy that both interventions incorporated a form of psychotherapy (i.e. problem-solving therapy) found previously to be effective against depressive symptomatology in an RCT with cancer patients [28]. Thus, both studies provide excellent examples of how a research-tested intervention can be incorporated into a broader intervention strategy designed for dissemination into clinical practice. The next phase in the development of this collaborative care model would be to identify strategies to facilitate its dissemination to practitioners working with cancer patients and to promote its implementation in oncology settings.

**Development of quality indicators of psychosocial care**

Persuading practitioners to implement recommended assessment and intervention strategies is perhaps the most difficult challenge facing efforts to promote evidence-based psychosocial care. My colleagues and I have shown that awareness of guidelines for the psychosocial care of cancer patients does not necessarily translate into adherence to those guidelines [29]. One useful conceptual framework for understanding and addressing this challenge is the push–pull infrastructure model [30]. The model stipulates that efforts to ‘push’ knowledge from research into practice must be accompanied by increased demand (i.e. ‘pull’) for evidence-based approaches by patients and providers and an increase in the capacity of the infrastructure to deliver evidence-based interventions. According to the model, when all three factors work in concert, the number of individuals providing and receiving evidence-based interventions should increase, thereby leading to improved outcomes [30]. To date, efforts to promote evidence-based psychosocial care have focused mostly on the push part of the model. For greater progress to be achieved, the model suggests that more attention needs to be devoted to fostering greater demand for evidence-based psychosocial care among the providers and the public and increasing capacity to deliver such care.

One way to foster greater demand and promote greater implementation of guideline recommendations is to measure and report on the quality of the psychosocial care that cancer patients receive. Along these lines, research has shown that medical oncology practices provided with feedback demonstrating their poor performance on certain quality indicators (e.g. recommending trastuzumab for women with HER-2/neu-positive breast cancer) relative to other practices demonstrated improvements over time on those same indicators [31]. Could psychosocial care for cancer patients likewise be improved by measuring and reporting to oncology practices their performance on indicators of the quality of psychosocial care?

To evaluate this possibility requires first that measurable indicators of the quality of psychosocial care be developed. Toward this end, I am leading a group within the American Psychosocial Oncology Society charged with developing and testing quality indicators. The goal is to produce indicators that: (1) can be measured easily and reliably by review of medical records; (2) demonstrate variability in performance across sites, which would suggest the potential for improvement; and (3) yield information that could be used to make decisions or take actions to improve quality. Following a review of relevant literature, including the IOM report [7] and the NCCN guidelines [11], indicators were developed to measure two components necessary for providing quality psychosocial care: a process for identifying distressed patients and a process for linking distressed patients with services. In terms of quality indicators, these components were operationalized by formulating two questions that could be answered yes or no based on the review of an individual patient’s medical record. First, is there documentation
indicating that the patient’s current emotional well-being was assessed? Second, is there documentation that action was taken if the patient was identified as having a problem with emotional well-being?

My colleagues and I are currently evaluating the performance of these and other quality indicators as part of the Florida Initiative for Quality Cancer Care. The project will eventually include patients first seen by a medical oncologist in 2006 for treatment of colorectal, breast, and non-small cell lung cancer at 11 sites located throughout the state of Florida. With regard to the psychosocial quality indicators, detailed rating criteria were developed for evaluating performance on the two indicators described above (available at www.cas.usf.edu/~jacobson). We recently reported performance on these indicators for 388 patients with colorectal cancer seen at seven different practice sites [32]. Our experience, borne out by periodic checks, is that the two criteria can be rated reliably following brief training of individuals who have experience reviewing medical records. More importantly, we found substantial variability on both measures across the seven sites. The percentage of patients for which there was evidence that emotional well-being was assessed within one month of their first visit with a medical oncologist ranged from 6 to 84% across the sites. Among those patients identified as having a problem with emotional well-being, the percentage for which there was evidence that action was taken to address the problem (or an explanation provided for why no action was taken) ranged from 0 to 100% across the sites. Additional information collected allowed us to compare the percentages in the same patients whose pain and emotional well-being had been assessed. Across all sites, there was evidence that pain was assessed in 87% of patients, while emotional well-being was assessed in only 60% of patients. These findings suggest that efforts to implement routine assessment of pain in cancer patients have, to date, been more successful than efforts to implement routine assessment of emotional well-being.

Resolved: all cancer patients should receive evidence-based psychosocial care

The rationale for promoting evidence-based psychosocial care is straightforward. With numerous studies demonstrating the efficacy of psychosocial interventions in reducing distress and improving quality of life in cancer patients, practitioners have an obligation to deliver care in a manner consistent with this evidence. Although the rationale is straightforward, there are major challenges to achieving the goal of translating psycho-oncology research into everyday clinical practice.

One challenge has been the nature of the evidence. Limitations that characterized many earlier studies, such as poor methodological quality and absence of eligibility criteria related to heightened distress, have been addressed in several recent studies. Another problem is that many intervention strategies shown to be effective have little potential for dissemination because of the time, expense, and resources required to implement them. This challenge is not insurmountable and can be addressed by designing new interventions with dissemination in mind or redesigning existing interventions to make them easier to disseminate. Also, intervention research needs to include evaluation of integrated forms of care delivery more relevant to clinical practice, such as the collaborative care model shown to be effective in treating depression in primary-care settings.

Making practitioners aware of evidence relevant to their clinical practice is another challenge. The publication of individual studies and even systematic reviews and meta-analyses appears to have had limited impact on practice. More promising approaches include targeted efforts at dissemination, such as the issuance of clinical practice guidelines and evidence-based recommendations for psychosocial care. By distilling relevant information and delivering it in a manner useful to practitioners, these approaches have greater potential to influence how care is actually delivered. These approaches will not succeed, however, unless practitioners can readily implement recommended interventions. Opportunities now exist for intervention developers to make their intervention materials (e.g. manuals, handouts) easily available to others via the Internet through web sites such as Cancer Control PLANET. In a similar manner, the membership of the International Psycho-Oncology Society should consider undertaking collaborations whereby members would work together to translate existing intervention materials into multiple languages and then make these materials available to others via the society’s web site.

As noted previously, perhaps the most challenging aspect of promoting evidenced-based psychosocial care involves situations where it would be advantageous to persuade practitioners to change how they deliver care. Change seems most likely to occur when, in addition to making information and materials available about evidence-based strategies (i.e. ‘push’), there is a desire on the part of practitioners and health-care organizations to adopt new ways of providing care (i.e. ‘pull’). One method of creating greater ‘pull’ with considerable promise is to develop a system that would allow practitioners and health-care organizations to perform self-evaluations of the quality of the psychosocial care they provide to cancer patients. Feedback that showed that the quality of psychosocial care was poor relative to other health-care
settings is likely to motivate change, especially if the quality metrics used are considered to be important and reliable and point to specific actions that can be taken to improve quality. Work conducted by my colleagues and I shows that it is possible to develop these types of quality metrics for psychosocial care and obtain information that can be used to guide quality improvement efforts.

A purported ancient Chinese proverb states, ‘May you live in interesting times.’ I believe these to be very interesting times for the field of psycho-oncology and that we are on the cusp of major changes that are likely to result in much greater availability of psychosocial services for people with cancer worldwide. The changes are driven by many forces including greater demand on the part of patients and their family members and greater recognition by our oncology colleagues of the important role of psychosocial care as part of comprehensive cancer care. The changes are also being driven by our growing evidence base, which demonstrates the efficacy of many psychosocial interventions in relieving distress and improving quality of life. To fully realize the potential for the field of psycho-oncology to positively influence the lives of people with cancer, we must focus on ways to ensure that the care provided on the ‘front lines’ is buttressed by research evidence demonstrating its value. By so doing, we increase the likelihood that we will have the support of our oncology colleagues and others to carry on our work. We also increase the likelihood that our services will have their intended positive effects on the lives of people with cancer.

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