Special Issue: From Distress Guidelines to Developing Models of Psychosocial Care: Current Best Practices

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From Distress Guidelines to Developing Models of Psychosocial Care: Current Best Practices

Paul G. Clark, PhD
George Mason University

Sage Bolte, PhD
Life with Cancer™

Joanne Buzaglo, PhD and Mitch Golant
Cancer Support Community

Louise Daratsos, PhD
Veterans Administration

Matthew, Loscalzo, MSW
City of Hope

Abstract

Psychological distress has been recognized as having a significant effect upon cognitive and emotional functioning, quality of life, and in some populations increased costs of care. Screening for distress and provision of psychosocial care in oncology treatment settings has been identified as a future accreditation standard by the American College of Surgeons Commission on Cancer (COC) (Commission on Cancer, 2011a). Because there are few available models of programs of distress screening and referral to inform oncology social workers and other members of the psychosocial support team with planning their own programs, this article seeks to provide exemplars of best practices that are currently in place in four different settings where psychosocial support is provided to people living with cancer and their families. Each program will provide an overview of how it was successfully established and its contribution toward evolving evidence-informed best practices.

From Distress Guidelines to Developing Models of Psychosocial Care: Current Best Practices

It is well known that depression, anxiety, and distress are complications of cancer that can appear at any point along the continuum of cancer care. Studies in outpatient settings have indicated that significant distress can be found in nearly one-third of cancer survivors at any given point in the cancer trajectory and that rate is nearly double among inpatients (Carlson et al., 2004; Carlson & Bultz, 2003; Clark, 2010; Clark, Rochon, Brethwaite, & Edmiston, 2011; Ford, Lewis, & Fallowfield, 1995; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Further, it is known that psychosocial screening and intervention can be used to ameliorate levels of cancer-related distress leading to improved coping, cognitive and emotional outcomes and improvement in quality of life (Andersen, 2002; Andersen, Shelby, & Golden-Kreutz, 2007; Carlson & Bultz, 2004; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Institute of Medicine [IOM], 2008; Meyer & Mark, 1995; Osborn, Demoncada, & Feuerstein, 2006; Rehse & Pukrop, 2003; Uitterhoeve et al., 2004).

More than a decade ago, the National Comprehensive Cancer Network (NCCN) established guidelines for managing distress; however, these guidelines have not been widely translated into screening and intervention programs (Jacobsen & Ransom, 2007). Recently, screening for distress has been identified as an accreditation standard by the American College of Surgeons Committee on Cancer (COC) (Commission on Cancer, 2011) and many cancer treatment centers are in the early stages of developing programs of screening and intervention in anticipation of the new accreditation requirements. Although there are well-developed practice guidelines available for creating distress management programs, translating them into practice can be challenging. This can be especially true when, as noted by Loscalzo, Clark, and Holland (2011), there are few models available that describe screening programs and practices for managing psychological distress among cancer survivors. To address this challenge, this article identifies common barriers to the development of psychosocial screening and intervention programs, explores components of best practices for psychosocial care, and provides exemplars of best practices that are currently in place in four different settings.

Barriers to Screening and Intervention

Barriers to screening and intervention range from the individual personal and professional characteristics of health care providers to environmental or organizational constraints. Personal and professional barriers can include knowledge, beliefs, values, assumptions, and level of skill (Schofield, Carey, Bonevski, & Sanson-Fisher, 2006). These barriers are often expressed through perceptions that screening is unnecessary, or outside the realm of what can be effectively treated or addressed in a cancer treatment setting (IOM, 2008; Jacobsen & Ransom, 2007; Schofield et al.) Professional avoidance of patients' psychosocial issues can also be a reflection of concerns about professional efficacy for managing a patient's emotional concerns (Girgis et al., 2009). These perceptions can be amplified in oncology care settings, especially when there is a lack of clarity about what constitutes distress, how psychosocial care should be provided or how to integrate psychosocial care into the clinical environment (IOM; Schofield et al.)

As health care organizations come under increasing pressure to accomplish more with fewer resources, time constraints are frequently identified as a significant barrier to identifying and addressing patients' psychosocial concerns (Frost, Brueggan, & Mangan, 1997; IOM, 2008; Schofield et al., 2006). Cost barriers and an absence of physical resources or reliable systems often interfere with the development of psychosocial screening and intervention programs as well (IOM, 2008; Jacobsen & Ransom, 2007; Schofield et al., 2006).

Locating and comprehending barriers that interfere with the development of a psychosocial screening and management program is necessary for creating approaches to address them. To encourage the development of a "culture of screening" as a component of best practices (Loscalzo, Clark, & Holland, 2011, p.456), it is essential that members of the psychosocial and health care teams and administrators are included in the development of the program from the outset.

Defining Best Practices

Ideally, best practices in psychosocial care of cancer patients emerge from practitioners and researchers engaging in collaborative outcomes research conducted within treatment settings. When implemented, best practices are responsive to the needs of patients, characterized by adaptability, and executed efficiently. Ultimately, best practices must be useful, feasible, and contextually relevant to the setting where they are implemented (Manela & Moxley, 2002). Additionally, it is essential that all stakeholders, from the members of the psychosocial team to administrators, are included in each phase of developing psychosocial screening and intervention programs.

Key Components of Best Practices Guidelines

The National Comprehensive Cancer Network (NCCN) (2012) and the Institute of Medicine (IOM) (2008) have developed research-based guidelines for identifying and managing cancer related distress. These guidelines identify four process components constituting best practices: (1) screening, (2) assessment, (3) treatment, and (4) follow-up. Guidelines also suggest when providers should engage in each of these processes. Systematic documentation of these processes in patients' medical records not only helps to ensure that patients are receiving care, but also increases the likelihood that members of the treatment team will know that psychosocial issues are being addressed. Finally, implementation of best practices requires formation of within-organization alliances to reinforce the implementation and the sustainability of best practices.

Screening. Screening involves rapidly identifying the degree of risk presented by patients' psychosocial challenges and unmet psychosocial needs, and ascertaining the degree to which help is desired (Mitchell, 2011). Screening should occur at the beginning of care and throughout treatment. Actively soliciting input about the selection of screening instruments and processes from members of the psychosocial care team, as well as clinical and administrative team members is essential for assuring the success of the program. Criteria for selecting valid and reliable screening instruments that can identify and quantify clinical levels of risk are reviewed elsewhere in this special issue (Rohan, 2012).

Assessment. Of principal importance is the immediacy of the response of the psychosocial team in performing assessments. Based upon screening results indicating moderate to severe distress or a request by a member of the care team, real-time or rapid assessment should follow. In other words, members of the psychosocial team should predictably respond to elevated or questionable screening results within a prescribed and, ideally, a short amount of time. The advantage to developing a systematized pattern of rapid and reliable response is that it ensures equitable provision of care, diminishes the likelihood that needs will be overlooked, and reduces concerns or reluctance by the medical staff and others about having to identify and manage psychological, emotional, and social issues on their own (Auxier, Farley, & Seifert, 2011). A comprehensive assessment includes gathering, analyzing, and synthesizing information about the presence of psychosocial issues that can challenge a patient's capacity for making health care decisions, managing illness, or maintaining quality of life. The assessment should include thorough exploration of psychological and behavioral symptoms including past behavioral health issues, suicidal ideation, use of medications substance-dependence, and concerns about body image and sexuality (NCCN, 2012). Further, the assessment should include an examination of existing social networks as well needs for support regarding financial and spiritual issues (IOM, 2008; NCCN, 2012).

Treatment/intervention. – Whether or not it is possible to provide intervention within every clinic or practice setting, formulating a plan for decreasing distress, enhancing health and restoring quality of life is an essential component of comprehensive and equitable cancer care. Whenever possible, the intervention plan should be as broad as possible and include providers with particular areas of expertise, such as oncology nurse educators, physical and occupational rehabilitation specialists, nutritionists, patient navigators and chaplains (Loscalzo et al., 2011; NCCN, 2012). When developed collaboratively with patients, intervention plans should lead to increased capacity for managing health challenges and any psychological, social, and spiritual consequences that may accompany them. Intervention strategies can include the provision of or referral for tangible materials or services as well as evidence-supported interventions that include cognitive-behavioral, problem solving, psychoeducational, supportive and family therapies (IOM, 2008; NCCN, 2012). When indicated, spiritual care can also be incorporated through referral to a spiritual counselor or chaplaincy services (NCCN, 2012).

Follow up/Re-evaluate. Comprehensive delivery of psychosocial screening and intervention includes providing follow-up information and service to the patient as well as the patient's family or other care providers. In addition, communication with the members of the oncology treatment team is an important component in the overall management of distress (Boyes, Newell, Girgis, McElduff, & Sanson-Fisher, 2006; McLachlan et al., 2001).

Re-evaluation through readministration of distress screening instruments can provide an indication if, following intervention, the patient's level of distress has improved or whether the intervention should be modified or replaced. In addition, documenting reductions in patient distress is a critical tool demonstrating to unit managers, department heads, and hospital administrators and executives the value of a psychosocial screening and social work intervention, and lend support to requests for additional staffing and resources.

Creating Organizational Alliances

For administrators, managers, physicians, and other members of the care team, management of time and costs are ever-present concerns. It is quite likely that, at least initially, any new program is going to be perceived as a minefield to be avoided. Engaging members of the psychosocial care team, the clinical team, and members of management and administrative teams will increase the likelihood that a psychosocial screening and intervention program will be successful (Loscalzo et al., 2011). Inclusion of stakeholders having varied responsibilities across the institution will ensure that program activities fit within systems of care and are perceived to be value-added. For example, administration of a patient survey in the waiting room will not be feasible if staff perceive the activity as a barrier or disruption to their own job responsibilities.

Obtaining a commitment from cancer committees, upper management, and treatment teams can be a protracted experience, but failing to enlist support from these entities from the start could jeopardize the success of implementing and sustaining a viable psychosocial program. Further, it is vital that reciprocal processes be developed among members of the psychosocial care team, clinical team, managers, and administrative entities (Loscalzo, Clark, & Holland, 2011; Talib, Rahman, & Azam, 2011; Vourlekis & Ell, 2007). Involvement of multiple stakeholders also will serve to educate them about patient distress and reinforce the notion that social workers are an essential front line responder to patients in distress. Further, demonstrating that psychosocial programs can add value, control costs, and reduce interruptions in the flow of care will enhance the likelihood that the program will continue to receive support.

Four Best Practices Models

Practice guidelines from multiple sources (e.g., NCCN, IOM, American College of Surgeons) have informed the development of four best practice models, which are presented here. Each model program provides a description of the nature of its setting, the evolution of the screening program that is currently in place in that setting, the management of challenges and barriers to the development of their program, and the lessons that have been learned an incorporated into the continuing refinement of the programs. The programs at the Veterans Administration New York Harbor Healthcare System –Brooklyn Campus and the City of Hope National Medical Center are exemplars of clinic-based programs, while Life with Cancer™ and the Cancer Support Community™ serve as model approaches to distress screening in community-based settings. Each best practice model reflects the differences in treatment settings, systems for delivering psychosocial interventions, use of technology in screening, and the patient populations served by each of the programs.

VA NY Harbor Healthcare System Brooklyn Campus

Nationally, 8.34 million of the 22.3 million Veterans in the US are enrolled in Veteran’s Administration (VA) healthcare system (National Center for Veterans Analysis and Statistics, 2011). In 2005, 2.1 % of cancer patients were treated at VA facilities (Howlader, Ries, Stinchcomb & Edwards, 2009). Demographic data for the local population served by this medical center is not publically reported, and Moye, Schuster, Latini and Naik (2010) note the scarce availability of data regarding Veterans and cancer. However, this urban VA hospital serves an ethnically diverse population reflective of the city (Brooklyn, NY) in which it is based as well as the general VA population in the US(Daratsos, 2011). Patients range in age range from the 20s to 90s. The patient population is almost exclusively male among Veterans of the older war cohorts (i.e., World War II, Korea and Vietnam) and includes more female Veterans in the newest cohorts of Desert Storm and the wars in Iraq and Afghanistan, mirroring the population shifts in the military. The top five malignancies are: prostate 29%, non-small cell lung cancer 12%, colon cancer 7%, melanoma 6% and bladder cancer 5% ("Site and Stage Distribution Report," 2009).

Within the oncology program, there are three oncology social workers. One social worker covers several oncology clinics in his location. Another social worker serves the inpatient medical ward, along with a senior social work coordinator dedicated to all the oncology outpatient clinics at her site. The senior social worker provides leadership regarding the psychosocial aspects of the entire Oncology Program. In all locations, the oncology social worker's primary responsibility is to assess the biopsychosocial needs of the Veteran and any individual designated as family. Other responsibilities include counseling, education about disease and treatment, provision of guidance regarding advanced directives, locating supportive services to enhance adherence, locating specialized mental health programs, and homecare and financial and benefits counseling. To meet the mandated changes of the COC 2015 standard, this VA Oncology Team proactively determined that it wanted to develop a process for distress screening. It formed an interdisciplinary committee for the purposes of determining the most appropriate screening tool and to pilot the screening tool in one clinic. The committee consisted of the Chief of the Service, the Program Administrator, the Nurse Manager/Patient Care Team Coordinator, a Clinical Psychologist, and the Oncology Coordinator, a social worker. We developed several criteria to determine the optimal screening tool for our program: It had to be user friendly to allow anyone to administer the tool or to allow a patient to self-administer it. The tool also had to be free of charge and easily converted into an electronic note suitable for the VA's computerized patient medical chart (CPRS) so that we could most easily collect and analyze screening data. Ultimately, the committee agreed that the instrument that best satisfied criteria was the NCCN Distress Thermometer (NCCN, 2012). The committee received approval from the medical center's medical records committee to add a template note to our medical records menu titled Psychosocial Distress Screening.

The Patient Care Team Coordinator trained the oncology triage nurses to administer the screening instrument and document the results for review by the rest of the team, especially the medical oncology attending and fellows, the clinical psychologist, and the oncology social worker. In the initial stages of the pilot, we also added a requirement that the triage nurse or the medical oncologist initiate electronic consult requests to the clinical psychologist and the oncology social worker. We deferred the question about when to rescreen.

Challenges

Despite optimism that all members of the clinical team as well as patients and family members would embrace the screening process, there were several challenges. The triage nurses did not have the benefit of being on the planning committee and were not as prepared as the clinical psychologists to introduce the instrument to the patient or facilitate completion of the instrument. The oncology fellows, while experienced physicians, had difficulty at times with managing many competing demands as well as reviewing the screening note, incorporating the data into their interventions and documentation, and generating psychosocial consults. For some patients, the distress screening process was confusing. Typically, these patients included those who had not developed a full understanding of the severity of their disease, patients receiving consultation to confirm the absence of disease, or those who had an established relationship with a VA mental health provider.

The inpatient social worker was unprepared to anticipate how the pilot would affect her own caseload and approach to the work. Given her other competing responsibilities, there were instances in which completing a distress note or engaging with other team members about a particular patient were postponed. Because of delays, the encounter with the patient might not reflect the same level of distress or the same set of distressing factors indicated in the initial screening. For patients with high levels of distress there was no systematic process in place to re-screen to determine if an intervention was effective.

Successes & Lessons Learned

Given that this was a pilot project, we anticipated some unevenness in how each clinician or each professional might participate in this endeavor. Perhaps because nursing triage is an essential component of this clinic, nurses consistently integrated the distress screen and documented the results in the patients' charts. Communication about a patient's score, however, was limited. As we reviewed the responses where there were high levels of overall distress or numerous endorsements of particular problems, we saw several opportunities for staff education. The opportunities included the identification of problem clusters regarding physical and emotional needs and accessing needed resources. In addition, we identified a need for improving systematic communication about levels of distress and areas of need among providers caring for the same patient. Finally, we are currently working toward including new groups of oncology fellows by making the distress screening process both user-friendly and integrated into their educational experiences.

The greatest contribution of the distress screening pilot is that it has served to highlight the importance of psychosocial oncology within the Oncology Program. It is moving psychosocial support away from a generic discipline specific policy toward developing policies and procedures that are integrated into the framework of a comprehensive interdisciplinary and patient-centered treatment matrix. More and more, Clinical Psychology and Oncology Social Work are collaborating and strategizing for engaging the Mental Hygiene clinics to improve services to our shared patients. The project has highlighted that psychosocial practice in the setting of an oncology program is a specialty area that demands highly trained, creative and ever curious social workers who want to lead the way in improving the lives of their patients.

Life with Cancer™

Life with Cancer™ (LWC) was founded in 1989 to address the emotional support and medical information needs of people living with cancer, their families, and concerned others. Service locations include a community-based setting and the inpatient oncology units in several of the hospitals within the hospital system to which LWC belongs. Services, provided at no charge, include brief counseling, personalized education about disease-specific treatment, children's programs, and provision of complementary therapies.

A move toward routine distress screening in both outpatient and inpatient service venues began in 2006 under the leadership of members of the LWC research committee that is comprised of clinician researchers. Although the need for screening had long been agreed upon among the members of the committee, establishment of the screening process involved several iterations. The final process reflected resolution of issues related to the selection of an appropriate instrument, use of technology to enhance compliance with screening, and securing administrative support for the cost of the screening program. Additionally, a screening protocol had to be developed that included identification of who would be responsible for conducting screenings, frequency of screening, how data would be shared between the data gatherer and the clinical staff for service planning, and how data could best be utilized for program planning within the organization.

The research committee reviewed several reliable and valid instruments for evaluating psychosocial distress, before deciding upon the eighteen-item Brief Symptom Inventory (BSI-18) (Zabora, Brintzenhofeszoc, Jacobsen, Curbow, & et al., 2001). Along with the BSI-18, a problem checklist and two Likert scale questions on pain and fatigue were developed. The problem checklist was adapted from the original problem checklist (NCCN, 2012) and was modified to reflect the services, resources and referrals Life with Cancer and the Cancer Services department could realistically provide. Factors that influenced the selection of these instruments included: time needed for administration, ease of use and education level required to complete the instruments, reliability and validity, establishment of clinical cut-off scores, availability in Spanish, the frequency of use within the oncology community both inpatient and outpatient, and the cost for the instrument and staff for conducting the screenings.

Rather than initiating screening with every client in every program, routine screening began with outpatient clients who had requested individual counseling or educational sessions with a social work or nurse clinician. As a strategy for successful implementation of the screening process, we took care to secure the support of the LWC administration, directors of the LWC educational and counseling programs, the business manager, clinicians and administrative support personnel.

Different protocols for distress screening and follow up were established for outpatient and inpatient settings. In the outpatient setting, data is gathered on patients, caregivers and/or family members through a first visit registration packet that can be completed online or on paper.

The registration packets include a self-administered demographic questionnaire, along with the BSI-18, a problem checklist and Likert scaled questions on pain and fatigue. Follow-up screening, offered at every third visit, or the last session (whichever comes first) includes the BSI-18 and the two Likert scale questions. A web link is available to participants who would like to complete the questionnaires online. Education group participants and time limited support group participants receive the instruments before the first session of the group and after the last session. Clinical staff members are responsible for providing these instruments to all new clients and/or groups, as well as tracking subsequent visits for follow up.

A pilot screening program began recently in a busy inpatient hematology/oncology unit served by LWC. Prior to the implementation of distress screening on the unit, it was essential that there was institutional support beyond the hematology/oncology unit. This required several meetings with administration, legal and medical records to not only ensure that all institutional policies and procedures were being followed, but to also increase the knowledge of these members about distress screening to elicit their ongoing support. All members were aware of the impending 2015 COC standards requiring psychosocial distress screening to maintain accreditation, and therefore were very willing to discuss how this could lay the groundwork for screening throughout the institution. Life with Cancer staff also supported the proposal to pilot distress screening on the oncology unit with the presentation of data on distress. Inpatient distress screening is administered to inpatients within twenty-four hours of their admission by a Life with Cancer administrative staff member. Additionally, a nurse case manager can arrange for a staff nurse to administer the packet that would be collected by a Life with Cancer staff member the following day. Follow-up screening procedures were not included in the pilot program, but will likely become a part of the future iterations of the inpatient-screening program.

Lessons Learned

As with any new venture, introducing distress screening provided many challenges and opportunities. In the outpatient setting, resistance emerged among psychosocial team members regarding time required for the staff members to track and identify both new clients and follow up visits. Solutions to this challenge included electronic screening options and enlisting administrative staff for registering patients and distributing screening packets.

Challenges with designing response time and protocols in the inpatient setting resulted in the development of a flow chart to guide staff in responding to the identified needs. For instance, if an individual's score indicates moderate to high distress, a LWC clinician is to follow up with the patient within the hour and provide a thorough psychosocial assessment. Moderate to high distress regarding somatic concerns, including pain and fatigue; require immediate notification of the patient's nurse. This course of action with respect to somatic concerns increased the support and buy-in of the hospital administration and medical team(s), as responsibility and liability issues was immediately addressed upon gathering data. A challenge that continues to arise in the inpatient setting is finding a location for completed screening instruments within the medical record in a manner that preserves confidentiality while also making the information available to the care team.

Formal outpatient screening has taken place for three years among clients seeking counseling or education services. The oncology counselors utilize the data to inform their individual sessions and discussion with the patient/family. The oncology nurse educators utilize the data gathered in ways that are most beneficial to the patient/family. For example, if an oncology counselor identifies that the patient has high somatic complaints and checks a box on managing side effects or sleep disturbance, she/he is able to collaborate and refer to the nurse educators to assist the patient with their concerns. Eventually, expansion of screening to include all LWC clients is anticipated but is dependent upon infrastructure changes that would support technology-driven screening at the full organizational level.

We have learned that there are several benefits to utilizing an online server to collect data. The data is directly entered into a database that has the ability to transfer the information to software like SPSS and Microsoft Excel. Additionally, completing forms online may provide participants with a greater sense of autonomy or privacy as they can respond in the privacy of their homes or wherever they access the site. Additionally, the web-based program provides the possibility of going completely paperless and wireless in our pre- and post-assessment questionnaires. This is a short-term goal of Life with Cancer's research committee, and likely to be implemented at bedside and outpatient with the use of touch pads during the 2012 – 2013 fiscal year.

Biopsychosocial Screening at City of Hope National Medical Center

Defining What Screening Means at City of Hope

At the City of Hope NCI designated Comprehensive Cancer Center in Duarte, California the distress screening program is rooted in this definition of biopsychosocial screening: The systematic process of proactively identifying physical, psychosocial, practical and spiritual problems linked with the provision of tailored educational information and resources simultaneously with triage to designated professionals to maximize the benefits of medical care and improve quality of life. This definition inspired the development of and automated instrument called "SupportScreen™," *(www.supportscreen.com)* (Loscalzo, Clark, Dillehunt, Rinehart, Strowbridge, & Smith, 2010) .

The *SupportScreen*™ is a HIPPA compliant touch screen interface that identifies mental and physical symptoms, psychosocial, spiritual and practical problems while providing tailored educational materials, automated triage, and clinical alerts to the physicians and designated health care professionals—all in real time. The data are maintained on a protected server for program development and research (Loscalzo, Clark, Dillehunt, Rinehart, Strowbridge, & Smith, 2010). Although *SupportScreen* has been well described elsewhere (Loscalzo et al., 2010) and is not the focus of this manuscript, some of the *lessons learned* about the culture change that was necessary in order to implement an automated comprehensive biopsychosocial screening program at the City of Hope are informative for planning similar approaches in other cancer settings. This is especially true as it relates to the emerging field of patient-facing technologies (Ahern, Woods, Lightowler, Finley, & Houston, 2011). Patient-facing technologies comprise the way that patients and or their families are actively and intuitively engaged by the technology in a variety of ways to maximize the quality and accuracy of context-sensitive information. There is no question that technology will be increasingly at the very core of health care processes as it has in other specialized professional and non-professional fields.

Building the Screening Program Together

Biopsychosocial screening is more likely to be accepted and valued, when, within the realty of the context of personal benefit, there is a comprehensive strategy for inclusion, engagement and implementation (Bultz, et al., 2011; Loscalzo, Clark, & Holland, 2011). Interdisciplinary teams of social workers, psychologists, psychiatrists, child life specialists, oncologists, health educators, nurses, rehabilitation therapists, chaplains, clinical nutritionists, researchers and patient navigators, created the content and processes of the biopsychosocial screening program at City of Hope. Simultaneously, the touch screen technology was created with the Information Technology Department as full partners. This process of true engagement and leveraging is an essential part of the culture change that is necessary to implement a biopsychosocial screening program.

Making Screening Work

The *SupportScreen*™, available in English and Spanish, has been in place as the standard of clinical care for almost three years at City of Hope with over 3000 outpatients screened. Screening occurs at first or second visit and, in the near future, screening will be repeated after 30 days or more. The content of the screening program is tailored to the specific needs of the population of patients being screened, for example, vaginal dryness in those patients in the gynecological and breast cancer clinics, attention to fertility preservation for patients of child bearing ages (and not in the geriatric patients). The timing of screening are also related to the needs of the patient and the way that cancer care is provided, for example, in surgery, screening is implemented at first visit since there is seldom a second visit before surgery. In addition, there are a number of physicians who want patients screened at every visit, given the integral role that the screening instrument plays in the clinical encounter. The touch screen technology allows for customizing the data that is collected. Uptake by physicians has been overwhelmingly positive. In two clinics, family caregivers/partners are also screened and a pilot screening program for inpatients is now underway.

Over the past four years, the Department of Supportive Care Medicine/ Sheri & Les Biller Patient and Family Resource Center has grown by well over 30% and in large part; this is attributable to the screening program data. A number of ongoing educational programs have been created as a direct result of the screening data. For example, there are now classes and groups focused on sleep, pain, nutrition, sexual functioning, gender strengths and problem solving. There is also a formal Patient and Family Orientation Class scheduled for new patients when they make their first appointment with a City of Hope physician.

At City of Hope, biopsychosocial screening helped create new patient/professional/staff partnerships through enhanced communication and coordination between the patient/family and their health care team and among the multispecialists themselves. The very act of getting all of the team members to openly discuss how they saw their clinical practice within the context of the specific screening items to be addressed, resulted in the emergence of an integrated interdisciplinary Department of Supportive Care that was entirely consistent with the patient-centered approach espoused by the IOM (2008) report.

Lessons Learned

Introducing the screening program at City of Hope had the benefit of institutional leadership with vision and courage to aspire to build the best program of supportive care services in the world. There was also a seasoned leadership team with extensive experience in the implementation of biopsychosocial screening programs and staff leadership models. Finally, and most important, was a team of professionals and support staff, who were able to turn fear into excitement, and build meaningful bridges across the institution to focus on what patients, families and our colleagues need.

Introducing any new program is always a challenge to the existing culture. Fortunately, biopsychosocial screening is an idea whose time has come, so there is considerable leverage to implement such programs. However, it is important to remember the basics about the introduction of any new program:

- Culture change is necessary to implement, sustain and grow
- Engaging other stakeholders, early on, reduces resistance to change
- Never take the support of your psychosocial colleagues for granted (feed your own family first)
- Make it easy---proceed in clearly defined manageable steps
- Start slow and very small--learn from your errors and fix them quickly
- Be very visible—predict that *there will be problems* and that they will be managed *by you*
- Share the data and glory with all the stakeholders (physicians, nurses, business managers, administrative support staff)
- Link the benefits (i.e., regulatory compliance, finances, quality, satisfaction, safety, research) with institutional values

Cancer Support Community

Nearly 85% of the 1.6 million new patients diagnosed with cancer are being treated in community cancer centers, hospitals, and private practices rather than in large comprehensive cancer centers (American Cancer Society, 2011; Cohen, 2002; Edwards et al., 2005). Given that the vast majority of cancer care is provided in community settings, it can often be difficult for patients and their families to receive the supportive services necessary to meet their biopsychosocial needs. To address these gaps, the Cancer Support Community (CSC) provides psychosocial services through nearly 50 local affiliates and over 100 satellite locations. Each community location provides support, education, and hope to all people affected by cancer at no cost. Programs include professionally-led support groups (online and face-to-face), individual counseling, educational and behavior change workshops, healthy lifestyle programs, social networking opportunities and personalized referral to resources.

To further bridge services gaps and identify solutions that will overcome barriers to ensure access to and provision of biopsychosocial care to cancer patients, the CSC tested the feasibility and effectiveness of community-based comprehensive screening for cancer patients. CSC accomplished this through a Demonstration Project using the Community Initiated Research Collaboration (CIRC) model (Golant & Thiboldeaux, 2010; Hunter, Lounsbury, Rapkin, & Remien, 2011; Lounsbury, Robinson, & Rapkin, 2007). CIRC is a translational research model that connects researchers with community members to enhance scientific knowledge and integrate sustainable evidence-based programming into the community. The CIRC model creates synergy among all stakeholders and partners across academic and local settings including community oncology practices, hospitals, and services providers such as CSC affiliates.

Demonstration Project: Study Aims

This Demonstration Project represents a priority initiative to establish quality standards for delivering integrative psychosocial care. The overall aim was to demonstrate that new patients seen within three different community settings could be screened for psychosocial distress and appropriately referred to community providers to address their specific concerns or sources of distress. These settings include a small oncology practice (five or fewer oncologists), a community hospital cancer center, and a community-based affiliate of CSC.Because more than half of cancer patients are seen in small practices (Patlak & Levit, 2009) that are often without resources for addressing patients' psychosocial needs, secondary aims of the small oncology practices were: to develop a structure that links cancer patients with distress to community services, and to identify patients at high risk for emotional distress in a community practice setting. In the community hospital setting the secondary aim was to develop a structure that integrates CSC services and education into a community cancer center to ensure that all patients are screened and referred for appropriate levels of psychosocial care. Another goal was to see that the screening, referral, and follow-up could be incorporated into the medical record and/or Electronic Health Record of patients. In the CSC community-based affiliate, the secondary aim was to screen new patients for psychosocial distress and make appropriate referrals within its own organization and to community providers. Further, screening data were used to plan for targeted program needs.

Methods

Implementing System-Wide Screening in the Community

In the Demonstration Project, CSC selected *SupportScreen*™ after a thorough scan of available screening tools, because it screened for problem-related distress as well as empowering patients to indicate the type of help or support they would like (e.g., print information, speak to a staff member). While *SupportScreen*™ is appropriate in a comprehensive cancer center or academic environment, screening for emotional and social needs within the community context might be different (IOM, 2008). Therefore, the City of Hope

(COH) and the CSC decided to collaborate on this community-based Demonstration Project to validate *SupportScreen*™ in the community.

Applying CIRC to Achieve Demonstration Project Aims

As a first step, CSC RTI engaged with three community partners to test the feasibility, acceptability and effectiveness of the *SupportScreen*™ system. During an initial 2-day retreat, the entire team joined in discussions to identify meaningful research questions that would result in relevant community-based outcomes. Embedded in these discussions were "process" conversations designed to build team cohesiveness by identifying challenges, anxieties, and hopes. The CSC affiliates developed their own protocol for the delivery of the screening system. Screening, assessment, triage, and referral options were adapted for each site and depended upon services available in each specific location. Affiliates also identified potential barriers and challenges to implementing the Demonstration Project including: lack of technical support; refusal of clinicians/colleagues to participate; patient fear of intrusion and loss of confidentiality; patients' refusal to be screened; and screening may identify needs they cannot meet. Time was taken to address each community practice concern including technology interfaces and coordination and integration with CSC affiliates. As an ongoing practice, all stakeholders and partners held weekly conference calls to discuss next steps and local adaptations conceived to achieve success.

Integrated Model of Community-based Screening, Referral, and Follow-up

Using the S*upportScreen*™ tool, trained oncology office staff implemented screening with incoming patients and facilitated a process to assure that all patients were referred as appropriate. High-risk patients were referred to case managers, and patients with moderate risk for psychosocial distress were referred to a CSC/Gilda's Club program. Community members that visited a CSC/Gilda's Club were met by a professional Patient Care Coordinator (PCC). The PCC reviewed and provided feedback to the patient based on their responses on *SupportScreen*™ and made recommendations about available programs targeted to the individual patient needs.

A structured accountability system was employed to provide referral, feedback and follow-up to the participating oncology practices. The coordinator at the community-based organization completed a simple form sent to the referring provider (e.g., oncologist) indicating that the patient came to the organization and received specific support. Patients treated at medical practices as well as those seen at a Community-Based Organization (CBO) were screened at their initial or second visit and then re-screened 30-45 days later.

Refining the Screening Tool for the Community

The three community partner sites participating in the Demonstration Project screened English-speaking, adult cancer outpatients upon their initial visit to the facility using touchscreen tablets. Screening became the standard of care at the participating sites, but patients could opt out of the screening. Immediately post-screening, patients received referrals and print information. Screening results were emailed to the physician, patient navigator and/or social worker. Patients were rescreened and completed a follow-up survey at 30 days.

A total of 84 of 85 patients (67% female, 93% white, 49% income<$40K) with mixed cancer diagnoses (38% breast, 15% lung, 12% colorectal) participated in the study. Most common problems (moderate to very severe) were sleeping (51%), worry about the future (50%), and fatigue (49%). As a result of receiving print information, participants (n=22) reported that 45% talked with a cancer specialist, 36% talked with program staff, and 27% attended an educational workshop or support group. As a result of receiving a referral, 45% talked with a cancer specialist, 30% talked to a healthcare provider other than a cancer specialist.

Based on these findings, CSC developed the streamlined CancerSupportSource™ (CSS), a low-cost 25-item web-based distress screening and referral instrument. CSS allows providers to rapidly screen and address patient distress needs, as well as allowing the aggregation of distress data system-wide. Reports are instantly generated including resource fact sheets related to each item on the survey and email alerts that can be customized for any institution. Specifically, CSS provides the patient a written *Personal Support Care Plan* with information and referrals for support services that can be emailed or printed as soon as they complete the survey. Providers receive a *Distress Management Report*—a summary score of a patient's results, including actionable clinical alerts to help staff triage a response. CSS is HIPAA compliant and can be linked to the electronic health record (EHR) using HL7 and web services interface.

Next Steps

CSC is implementing CSS in two of its affiliates as well as two oncology practices that are members of the American College of Surgeons Commission on Cancer (ACOS CoC). In addition, one of the community practice sites is a member of NCI's National Community Cancer Centers Program and the Association of Community Cancer Centers. The goal is to ensure that all cancer patients are screened, referred, and provided follow-up for their psychosocial needs to meet the IOM mandate that psychosocial care is integrated as a standard of quality cancer care.

Discussion and Conclusion

Best practices in psychosocial screening and intervention programs are not simply a collection of exemplary practice methods. They are built upon and bound by processes that consistently strive toward providing integrated and comprehensive psychosocial care. Each program presented here was initiated by members of psychosocial care teams that provided an infrastructure for incubating and supporting the processes that have emerged as current best practices. However, the development of best practices in psychosocial screening and intervention in the programs illustrated here did not result solely from efforts made by members of the psychosocial support teams. Rather, they were the result of collaborative alliances, carefully built between and among many stakeholders that included administrators, information technologists, and the members of multidisciplinary teams involved in the patient care process.

In each of the exemplars presented in this article, best practices in psychosocial screening and intervention programs emerged slowly through sustained and inclusive processes that engaged stakeholders at each stage of program development from screening through re-evaluation. It is noteworthy that for most of the programs, preparation and evolution of screening programs took a great deal of time and focus as they grew from small pilot studies or small scale attempts at implementation toward functioning programs that have become an integral part of the systems in which they are situated.

In addition, each program anticipated, expected, and faced similar challenges and sources of resistance and used a number of strategies to address them. It is unlikely that the competition for diminishing resources in health care settings will become less intense in the future, and challenges to providing services in all areas of health care are likely. Anticipating resistance and making use of data-driven evidence to demonstrate the value added by the psychosocial screening and intervention program, and doing so frequently and overtly, is essential. In some respects, the reality of diminishing resources compels the development of best practices models to strive for better and more effective performance and outcomes (Manela & Moxley, 2002).

While the new COC accreditation standard for psychosocial distress screening may be perceived as challenging, it is also an affirmation that psychosocial care has reached a new level of acknowledgment. The development of this standard heralds the importance of psychosocial care as an important dimension in the provision of quality personalized care that embraces the biopsychosocial model.

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