



PSYCHOSOCIAL DISTRESS SCREENING

**Lessons Learned
from Three
ACCC Member
Programs**

ASSOCIATION OF COMMUNITY CANCER CENTERS

11600 Nebel Street, Suite 201
Rockville, MD 20852
301.984.9496 • accc-cancer.org

Association of Community Cancer Centers
This publication is a benefit of membership.





CONTRIBUTORS

ASSOCIATION OF COMMUNITY CANCER CENTERS (ACCC)

Amanda Kramar

Director, Provider Education

Marianne Gandee, MA

Assistant Director, Provider Education

Monique J. Marino

Manager, Publications

Amanda Patton

Manager, Communications

ACCC ADVISORY COMMITTEE

Jeff Kendall, PsyD

*Associate Professor, Clinical Leader
Oncology Support Services UTSW Simmons Cancer Center*

Lori McMullen, RN, MSN, OCN

*Senior Oncology Nurse Navigator
University Medical Center of Princeton at Plainsboro*

Fran Becker, LCSW

*Manager, Cancer Support Services
Bennett Cancer Center*

Deidre Robinson

*Social Worker
Gwinnett Medical Center*

AMERICAN PSYCHOSOCIAL ONCOLOGY SOCIETY (APOS)

Teresa Deshields, PhD

*Manager, Siteman Counseling Service
Siteman Cancer Center, Barnes-Jewish Hospital
Clinical Associate Professor, Department of Medicine
Washington University School of Medicine*

Bradley Zebrack, PhD, MSW, MPH

*Professor, School of Social Work
University of Michigan*

Lynne S. Padgett, PhD

*Program Director, Behavior Research Program
National Cancer Institute*

Mark Lazenby, PhD, FAPOS

*Associate Professor
Schools of Nursing & Divinity & Council on Middle East Studies
Yale University*

Michelle Fingeret, PhD

*APOS President, Associate Professor, Director Body Image Therapy Program
MD Anderson Cancer Center*

Jimmie C. Holland, MD

*Founding President, APOS
Wayne Chapman Chair in Psychiatric Oncology
Memorial Sloan Kettering Cancer Center*



A special thanks to

STAMFORD HOSPITAL

Carl & Dorothy Bennett Cancer Center

**CHI HEALTH GOOD SAMARITAN
CANCER CENTER**

**UT SOUTHWESTERN
MEDICAL CENTER**

**Harold C. Simmons Comprehensive
Cancer Center**

*Funding and support
provided by*





TABLE OF CONTENTS

PSYCHOSOCIAL DISTRESS SCREENING LESSONS LEARNED FROM THREE ACCC MEMBER PROGRAMS

- 2** Distress Screening 101
- 3** An ACCC/APOS Collaborative Project
- 4** Site Visit 1 – *Carl & Dorothy Bennett Cancer Center*
- 6** Carl & Dorothy Bennett Cancer Center Distress Screening Process Flowchart
- 8** Site Visit 2 – *Harold C. Simmons Comprehensive Cancer Center*
- 10** Harold C. Simmons Cancer Center Distress Screening Process Flowcharts
- 12** Site Visit 3 – *CHI Health Good Samaritan Cancer Center*
- 14** CHI Health Good Samaritan Cancer Center Distress Screening Process Flowchart
- 16** Challenges to Distress Screening
- 17** Key Recommendations
- 19** Project & Survey Methodology
- 20** References



DISTRESS SCREENING 101

Within the past 20 years, the field of psychosocial oncology has made great strides with regard to advocating for the implementation of distress screening. A growing body of research documents the prevalence of distress among adults with cancer, the consequences of unmet psychosocial health needs of cancer patients and their families, the availability of effective interventions to address distress in the oncology setting, and improved outcomes from distress screening and referral.¹⁻³

Oncology care has been heavily influenced by consensus-based guidelines first developed in 1997 by the National Comprehensive Cancer Network (NCCN) for the identification and treatment of psychological distress in cancer. In 2009 the International Psycho-Oncology Society (IPOS) endorsed distress as the “sixth vital sign,” recommending regular screening for distress alongside temperature, blood pressure, pulse, respiration, and pain.⁴ Beginning in 2015, the American College of Surgeons Commission on Cancer (CoC) has required cancer centers to implement programs for psychosocial distress screening as a criterion for accreditation. Quality care standards for distress screening have been endorsed by the leading psychosocial professional organizations, including APOS, AOSW, and ONS.² ASCO has also adopted clinical guidelines for the screening, assessment, and care of psychosocial distress.⁵

There are several fundamental components a distress screening program must systematically address in order to meet current quality care standards.^{6,7} While CoC Standard 3.2 requires that a clear process be delineated for conducting on-site screening activities *a minimum of one time per patient*, it is left up to each program to determine which pivotal medical visit is selected. NCCN clinical practice guidelines more specifically suggest that screening be conducted for all patients at their initial visit and at additional time points when patients undergo changes in disease status. Continuous screening for distress using validated instruments with established cutoffs would be considered a gold standard method.² Once distress is identified, a clear process must then be used to further evaluate patients and link them with appropriate psychosocial resources (on site or by referral). Finally, all screening, referral, and follow-up activities must be documented in the medical record.

Once distress is identified, a clear process must then be used to further evaluate patients and link them with appropriate psychosocial resources.



AN ACCC / APOS COLLABORATIVE PROJECT

Distress screening is endorsed as a component of quality cancer care by the National Comprehensive Cancer Network (NCCN), the American College of Surgeons Commission on Cancer (CoC), the Institute of Medicine (IOM), and the American Society of Clinical Oncology (ASCO). Research suggests that screening for distress and managing distress enhance quality of life and are associated with improved medical outcomes.^{8,9} In 2014 a joint task force of the American Psychosocial Oncology Society (APOS), the Association of Oncology Social Work (AOSW), and the Oncology Nursing Society (ONS) endorsed the following as critical elements of a comprehensive distress screening program:²

- Use of a validated screening tool
- Qualified on-site psychosocial clinicians
- Incorporation of distress screening into routine medical care; appropriate training for the entire cancer team
- A system for 1) administering screening, 2) reviewing the results of screening, 3) conducting follow-up with distressed patients, and 4) referring distressed patients for needed services.

OUR PROJECT

In 2015 the Association of Community Cancer Centers (ACCC) and APOS partnered to study ACCC member programs with successful distress screening programs in order to identify practices and strategies that may help with the implementation of distress screening at other sites. The project goal: to improve the patient experience and overall patient care. Learn more at accc-cancer.org/distress-screening.

In partnership, APOS and ACCC designed selection criteria for identifying cancer programs that have been successful at implementing distress screening. Eligibility and evaluation criteria (pages 19 – 20) were developed to select three pilot sites. (Methodology behind pilot site selection can be found on page 20.) The project team sought to ensure that the pilot sites they chose represented a diversity of settings and patient populations. Active ACCC membership and evidence of a well-functioning psychosocial distress screening program were baseline eligibility requirements. ACCC provided a list of member candidate sites meeting these criteria; APOS also recommended a number of programs to add to this list. Using these baseline criteria, APOS designed a two-step selection process. ACCC retained the right to make the final determination of sites to visit. The three sites selected were:

- **Bennett Cancer Center – Stamford, Connecticut**
- **Simmons Cancer Center – Dallas, Texas**
- **CHI Health Good Samaritan Cancer Center – Kearney, Nebraska**

The project team visited these three sites to study their distress screening process and identify effective practices to be shared with other cancer programs. The team then identified key findings and developed process flowcharts from these site visits.



SITE VISIT 1

Carl & Dorothy Bennett Cancer Center

Stamford Hospital, Carl & Dorothy Bennett Cancer Center, Stamford, Connecticut, is a 305-bed not-for-profit community hospital in a suburban setting. The cancer center provided care to 936 new patients in 2014. Racial minorities made up 13 percent (including 10 percent African American) of the cancer patient population; additionally, 8 percent of the cancer patient population identified themselves as Hispanic. The cancer center is accredited by the American College of Surgeons as an Academic Comprehensive Cancer Program. The site visit team met with a multidisciplinary team, including:

- The manager of Cancer Support Services
- The director of Cancer Services
- The medical director
- The cancer program manager
- The distress screening coordinator
- A social work intern
- The IT specialist for medical oncology
- The coordinator of the Survivorship Program
- A medical oncologist
- A simulation technologist for Radiation Oncology
- The manager for Radiation Oncology
- The chief physicist for Radiation Oncology.

TOOLS & RESOURCES

Bennett Cancer Center uses the NCCN Distress Thermometer and Problem List to conduct distress screening. A positive score is considered 5 and above (0-10 scale). In addition to English, the screening tool is available in four languages—Spanish, French Creole, Polish, and Russian.

The cancer center offers a number of resources for their cancer patients (distressed or not), including the STAR (Survivorship Training and Rehabilitation) Program, an exercise program for certain cancer patients at an associated fitness center, nurse navigators, an ostomy nurse, and social work support (one social worker, social work interns). Other resources include a patient resource library, genetic assessment and counseling, palliative care, nutrition counseling, transportation assistance, pastoral care, and integrative therapies (Reiki, reflexology, massage, craniosacral massage, yoga, art therapy, music therapy), and patient education programs, including a survivorship conference.



DISTRESS SCREENING PROGRAM

Bennett Cancer Center implemented its distress screening program in 2009. Screening is done at four touch points:

1. At the initial Medical Oncology visit, the front desk staff gives new patients the distress screening tool.
2. At the end of medical oncology treatment, the survivorship nurse has patients complete the distress screening tool.
3. At the beginning of radiation oncology treatment, the simulation technologist administers distress screening.
4. At the end of radiation treatment, the manager for Radiation Oncology has patients complete the distress screening tool.

The Medical Oncology scheduler looks at the weekly patient appointments and identifies the patients that should be screened. She also tracks whether the screening results were distributed as planned. Distress screening takes about two hours/per week of her time.

Patients complete a paper-and-pencil version of the NCCN Distress Thermometer and Problem List. The paper form is then scanned into the electronic health record (EHR). In Medical Oncology, the patient gets a copy to take into his or her initial consultation with the oncologist. A copy goes to the cancer center social worker. A positive screen is considered to be a score of 5 or greater on the Distress Thermometer.

In Medical Oncology, the oncologists note the distress score in the Review of Systems in the EHR and the relevant problem areas in the psychosocial section. There are three set responses for the plan of action in the psychosocial section:

1. Patient agreed to contact by Cancer Support Services
2. Patient declined contact by Cancer Support Services
3. Patient declined to complete the form.

When the physician makes a referral, it generates an alert for the referral target. The social worker follows up with the physician (via email) when there is a positive screen in Medical Oncology. In Radiation Oncology, the social worker can put notes into the EHR documenting response to the screen.

Patients are informed about distress screening by staff that performs screening. Patients that have a negative screen (score = 1-4) are sent a letter telling them about available services. For patients that have a positive screen (score > 5), the social worker calls or meets with the patient for assessment of need. The time frame for follow-up depends on the score—higher scores receive faster responses—but follow-up occurs within 24 to 48 hours of receiving the screening result. Staff training about distress screening occurs in educational in-services.

PROGRAM SUCCESSES

In 2014, Bennett Cancer Center screened 793 of 935 total new patients. The cancer center has a number of multidisciplinary staff trained in the STAR program for their cancer survivors. Further, the cancer center has identified three current and future initiatives:

1. To increase the frequency of screening, particularly to assess distress midway through treatment.
2. To increase the frequency of screening for patients getting oral chemotherapy—who are not coming in to the infusion center. These patients are currently screened at the initial visit to Medical Oncology and at the survivorship visit.
3. To upgrade the survivorship program to a freestanding survivorship clinic.



CARL & DOROTHY BENNETT CANCER CENTER FLOWCHART

Distress Screening Process 2015

- 1,000 new patients per year
- Infusion: 45 patients per day



Step 1

Distress screening initiated in 2009.
1 social worker, between 2 to 4 social work interns, 4 nurse navigators, and a genetic counselor available on site.



DEFINING PIVOTAL POINTS:

Patients screened at first medical oncology visit and again at the end of medical oncology treatment; patients screened at first radiation oncology visit and again at the end of radiation oncology treatment.

Surgical oncology and ER patients currently not screened; working toward electronic distress screening across all service lines.

Step 10a

Social worker follows up with physician referrals on the EHR.

~ or ~

Step 10b

In Radiation Oncology, the social worker enters score into the EHR.





Step 3

Front desk staff ask patients to complete a paper-and-pencil version of the NCCN Distress Thermometer and Problem List.

Step 4

The paper form is then scanned into the electronic health record (EHR).



Step 5

The patient gets a copy to take into his or her initial consultation with the oncologist; physician reviews the distress screening score during the patient visit.

Step 2

The medical oncology scheduler looks at the weekly patient appointments and identifies the patients that should be screened.



Step 6

A copy goes to the cancer center social worker. A positive screen is considered to be a score of 5 or greater on the Distress Thermometer.

Step 9a

Physician and social worker review the screens independently. For patients that have a positive screen (score > 5), physician makes a referral, which generates an alert for the referral target. The social worker then calls or meets with the patient for assessment of need. The time frame for follow-up depends on the score—higher scores receive faster responses—but follow-up occurs within 24 to 48 hours of receiving the screening result.

Step 8a

Patient agrees to contact by Cancer Support Services.



Step 7

The oncologist enters the distress screening score into the EHR.

Step 9b

Patients that have a negative screen (score = 1 to 4) are sent a letter telling them about available services.

Step 8b

Patient declines contact by Cancer Support Services.

Step 8c

Patient declines to complete the form.





SITE VISIT 2

Harold C. Simmons Comprehensive Cancer Center

UT Southwestern Medical Center, Harold C. Simmons Comprehensive Cancer Center, Dallas, Texas, is located in an urban setting in a large metropolitan area. The cancer center is part of a large university-affiliated academic medical center with 460 beds where care was provided to 3,600 new cancer patients in 2014. Racial and ethnic minorities make up 33 percent of the cancer patient population (approximately 15 percent African American; 13 percent Hispanic; 4 percent Asian; 1 percent other). Simmons Cancer Center is a National Cancer Institute (NCI)-designated cancer center. The site visit involved a multidisciplinary team, including:

- The associate vice president for Cancer Programs
- The director of Ambulatory Oncology Operations
- The assistant director for Oncology Support Services
- The clinic manager for the Bone Marrow Transplantation/Hematologic Malignancy Clinic
- Nursing supervisors
- Oncology social workers
- A clinical dietitian
- Two IT specialists.

TOOLS & RESOURCES

The Simmons Cancer Center distress screening tool originated from the Edmonton Symptom Assessment Scale. Screening is verbally administered by a nurse as part of the nursing assessment. The five screening questions include: a nutritional assessment, followed by three independent ratings on a 0-10 scale (depression, anxiety, and spouse or family concerns) and then a question about whether the patient would like contact from a support services professional. Two Spanish-language interpreters are tasked specifically to the cancer center for office visits. There is also a medical assistant in the Bone Marrow Transplantation Program who is a certified Spanish-language interpreter. If needed, the medical teams use telephone interpretation services.

Simmons Cancer Center has a number of resources available for patients. A cancer psychologist and four full-time equivalent (FTE) social workers provide counseling support. Simmons Cancer Center has two outpatient dietitians who see all patients for pre-screening before they start chemotherapy. Additional resources include music therapy, physical



therapy, a palliative care team (physician, nurse practitioner, social worker), and financial counselors who connect with patients before their first visit to the cancer center. Simmons Cancer Center also offers a series of survivorship classes focused on exercise, mindfulness, and coping.

DISTRESS SCREENING PROGRAM

Simmons Cancer Center established its distress screening program in 2011 after the associate vice president for Cancer Programs hired a psychologist to develop this type of program for the cancer center. (The psychologist had developed a distress screening program at the cancer center where he previously worked.)

Distress screening is done at every office visit by nurses in Medical Oncology and Surgical Oncology in the clinic room or by nurses in the chemotherapy infusion center. Patients are first asked about nutritional changes and then asked to make the three verbal ratings (depression, anxiety, and spouse or family concern) on a 0-10 rating scale. Patients are also asked whether they want to be contacted by the oncology dietitian, cancer psychologist, cancer social worker, or a medical center chaplain. The responses are immediately entered into the EHR, which is shared by Medical Oncology and Surgical Oncology. An indication of nutritional changes and/or a score of 8 or above on any of the 3 rating scales is considered a positive screen and triggers an electronic alert through the EHR to the relevant resource. Dietary issues alerts to the dietitian, anxiety or depression alerts to the psychologist, and spouse or family concerns alerts to social work. When a provider follows up to an alert, a note is entered into the EHR. Patients are also referred if they indicate interest in being contacted by one of the listed providers.

Patients are educated about distress screening by the nurses in the clinic setting, with efforts to normalize both the experience of distress, as well as referral to cancer center resources. Staff is educated about distress screening through in-services provided by the cancer psychologist.

PROGRAM SUCCESSES

Simmons Cancer Center's initial screening program, which was implemented in 2011, relied on a paper-and-pencil tool. This process generated some challenges in terms of tracking the paper screening tool and timely alerting of relevant staff to a positive screen. The site implemented the electronic screening protocol (described above) in 2015. There have been 2,512 to 2,843 screenings per month with the new system, with 8 to 11 percent of screens being positive. Simmons Cancer Center has identified three current and future initiatives:

1. To research the impact of distress screening on medical utilization.
2. To grow the education and training mission for Oncology Support Services. Simmons Cancer Center thinks that bringing in trainees may help to extend their clinical capabilities.
3. To change to a validated standardized screening tool, but Simmons Cancer Center acknowledged that this is unlikely to happen.



HAROLD C. SIMMONS CANCER CENTER FLOWCHARTS

Distress Screening Process

- 3,600 new patients per year
- Infusion: 65 patients per day

2015 to Present



Step 1

Distress screening initiated in 2011.
7 social workers (4 OP, 3 IP),
1 psychologist, 2 dietitians,
3 music therapists.



DEFINING PIVOTAL POINTS:

Distress screening is done at every office visit by nurses in Medical Oncology and Surgical Oncology in the clinic room or by nurses in the chemotherapy infusion center.

Step 8

Staff documents patient contact in the EHR.



Step 7

If patient is seen beyond the 48-hour threshold, staff notes in EHR that distress screening follow-up will occur in person on the following appointment date.

2011 to 2014



Step 1

Distress screening initiated in 2011.
Team includes 7 social workers
(4 OP, 3 IP), 1 psychologist,
2 dietitians, 3 music therapists.



DEFINING PIVOTAL POINTS:

Distress screening is done at every office visit by nurses in Medical Oncology and Surgical Oncology in the clinic room or by nurses in the chemotherapy infusion center.

Step 10

Staff documents patient contact in the EHR.



Step 9

If patient is seen beyond the 48-hour threshold, staff notes in EHR that distress screening follow-up will occur in person on the following appointment date.

Step 8

Staff responds to distress screening form by contacting patient by phone and in person within 24-48 hours. When a provider follows up to an alert, a note is entered into the EHR.



Step 2

During assessment, nurses verbally ask patients the distress screening questions and enter responses in the EHR. Patients are asked about nutritional changes and then to make three verbal ratings (depression, anxiety, and spouse or family concern) on a 0-10 rating scale. Patients are also asked whether they want to be contacted by the oncology dietitian, cancer psychologist, cancer social worker, or a medical center chaplain.

Step 3

An indication of nutritional changes and/or a score of 8 or above on any of the 3 rating scales is considered a positive screen, which creates an automatic referral within the EHR to the appropriate supportive care team member.

Step 4

Dietary issues alerts to the dietitian, anxiety or depression alerts to the psychologist, and spouse or family concerns alerts to social work.

Step 6

Staff responds to distress screening form by contacting patient by phone and in person within 24-48 hours. When a provider follows up to an alert, a note is entered into the EHR.

Step 5

Patient requests for specific services are sent to the appropriate staff member(s).



Step 2

Front desk staff gives paper distress screening form to all patients. Patients complete the form in the waiting area and return it to front desk staff.

Step 3

Patients are first asked about nutritional changes and then asked to make three verbal ratings (depression, anxiety, and spouse or family concern) on a 0-10 rating scale. Patients are also asked whether they want to be contacted by the oncology dietitian, cancer psychologist, cancer social worker, or a medical center chaplain.

Step 4

Social workers collect distress screening forms from front desk staff. If distress screening forms are found at other locations in the clinic, team members will return them to front desk staff and/or the social worker.

Step 7

Social worker does an additional screening of distress screening forms where patients have requested contact with billing.



Step 6

Social worker distributes distress screening forms where patients request supportive care services to the appropriate team member(s).

Step 5

An indication of nutritional changes and/or a score of 8 or above on any of the 3 rating scales is considered a positive screen. Social worker distributes positive screens; dietary issues go to the dietitian, anxiety or depression goes to the psychologist, and spouse or family concerns go to social work.



SITE VISIT 3

CHI Health Good Samaritan Cancer Center

CHI Health Good Samaritan Cancer Center, Kearney, Nebraska, is a 268-bed not-for-profit community hospital located in a rural setting.

The cancer center provided treatment to 496 new patients in 2014. Racial and ethnic minorities made up 5 percent of the cancer patient population. CHI Health Good Samaritan Cancer Center is accredited by the American College of Surgeons Commission on Cancer (CoC). The site visit involved a multidisciplinary team, including:

- The director of Oncology Services
- The oncology services manager
- A patient and family counselor
- A cancer nurse navigator
- An oncology nurse practitioner
- The manager of Behavioral Health Business Operations.

TOOLS & RESOURCES

CHI Health Good Samaritan Cancer Center uses the NCCN Distress Thermometer and Problem List; inpatients complete only the Distress Thermometer. The cancer center has included additional items under the "Other Problems" section: driving, speaking, swallowing, weakness, and chores and shopping to assist with cancer rehabilitation screening. A positive screen is considered to be a score of 4 or above. The screening tool is available in Spanish.

The navigators have created a resource center with educational handouts to match every problem on the NCCN Problem List. Many of these handouts are NCI teaching sheets. CHI Health Good Samaritan Cancer Center has many resources available to patients, including:

- Financial assistance for breast and cervical cancer patients through the Visiting Nurse Association in Nebraska
- Kearney Tackles Cancer, a local philanthropic program that provides some financial assistance for patients with any cancer diagnosis
- Pastoral care
- STAR® Program, a cancer rehabilitation program
- Counseling
- Tobacco cessation
- Pet therapy
- Complementary therapies (aromatherapy, massage therapy)
- Genetic counseling



- Support groups
- Cognitive therapy
- A public benefit specialist
- Richard Young Outpatient Clinic, a full-service psychiatric outpatient/inpatient department of CHI Health Good Samaritan.

CHI Health Good Samaritan Cancer Center also offers some programs in conjunction with the local American Cancer Society, specifically Look Good Feel Better and volunteer drivers. The local Area Agency on Aging provides transportation and housecleaning assistance for cancer patients over 60 years of age.

DISTRESS SCREENING PROGRAM

CHI Health Good Samaritan Cancer Center started developing its distress screening program in 2009 after the site participated in the National Cancer Institute (NCI) Community Cancer Centers Program (NCCCP). Screening is accomplished at different touch points. Outpatient radiation oncology patients are screened at their first visit to Radiation Oncology and at the first visit of each successive month. In the chemotherapy infusion center, patients are screened at their first visit and at each subsequent chemotherapy visit—but not more than weekly. For inpatients with cancer, the cancer center nurse navigators complete screening with the Distress Thermometer (without the Problem List) sometime during the admission process.

Front desk staff members give outpatients a paper-and-pencil NCCN Distress Thermometer and Problem List, which patients complete while waiting for clinical care. The completed screen is scanned into the EHR. Nurse navigators receive the paper tool and enter patients' responses into the psychosocial section of the EHR. For a score of 4 to 6 on the Distress Thermometer, the navigator refers the patient to the cancer counselor (or other appropriate resource). For a score of 7 to 10, the navigator refers the patient to the cancer counselor (or other appropriate resource) and attempts to arrange contact on the same day.

Nurse navigators see all patients at their first visit to Radiation Oncology and their first visit to the infusion center; the navigators receive an alert through the EHR. Patients are educated about distress screening by the navigator, including the fact that screening will be done approximately once a month. Navigators work to normalize emotional concerns for patients. The navigators give new patients a brochure about navigation and educational handouts, as appropriate, from the resource center. As stated previously, CHI Health Good Samaritan Cancer Center has patient handouts for every problem listed in the distress screening tool.

The Oncology Services manager educates staff about distress screening during their orientation; this education is an item on the orientation checklist.

PROGRAM SUCCESSES

CHI Health Good Samaritan Cancer Center obtained a NCCCP grant through its parent organization, Catholic Health Initiatives. An ARRA (American Recovery and Reinvestment Act) grant from the NCCCP funded a tobacco cessation counselor position for three years. The cancer center used this time to demonstrate the need for a counselor. When the grant ended, the position transitioned to a patient and family counselor role, which includes tobacco cessation work and is now institutionally funded. CHI Health Good Samaritan Cancer Center has also developed philanthropic funding streams by partnering with local agencies and high schools. The cancer center has been able to expand from one to three cancer nurse navigators. CHI Health Good Samaritan Cancer Center has identified four current and future initiatives:

1. To move to a tablet format for distress screening with automatic entry of data into the EHR.
2. To set up alerts in the EHR as to when distress screening should be done.
3. To create additional space for patient consultations in the clinical setting.
4. To add the services of a dedicated cancer center financial counselor and a social worker.



CHI HEALTH GOOD SAMARITAN CANCER CENTER FLOWCHART

Distress Screening Process 2015

- 500 new patients per year
- Infusion: 15-18 patients per day
- Radiation: 25-35 patients per day



Step 1

Distress screening initiated in 2009.
1 counselor and 3 RN navigators on site.
Behavior Services available off campus.



DEFINING PIVOTAL POINTS:

Patients screened at first visit to radiation oncology and first visit to infusion center; patients then screened (at minimum) at first visit of each subsequent month.

Medical oncology services provided by private practice located outside of the hospital. Currently not screening patients for distress.

Step 11

Nurse navigator documents patient response and STAR referral in EHR.



Step 10

Nurse navigator contacts physician for STAR Program referral.

Step 9a

Nurse navigator contacts STAR Program coordinator.



~ or ~

Step 9b

Nurse navigator documents patient response in EHR.



Step 3

Navigator receives distress screening forms, checks scores, and enters problem list responses into EHR; navigator visits new patients in radiation oncology and infusion center.

Step 2

Patient signs in at front desk and receives intake packet, including distress screening form. Patient fills out and returns to radiation nurse or nurse navigator.

LOW DISTRESS - (SCORE OF 0-3)

Step 4a

- Navigator reviews distress screening with patients
- Education and referrals if appropriate

~ or ~

MODERATE DISTRESS - (SCORE OF 4-6)

Step 4b

- Navigator reviews distress screening with patients
- A referral is made to the LMHP (licensed mental health practitioner)
- Additional medical staff notified, as indicated by assessment
- Education and referrals to address needs and barriers

~ or ~

HIGH DISTRESS - (SCORE OF 7-10)

Step 4c

- Nurse verbally notifies nurse navigators of high distress
- Navigator reviews distress screening with patients
- A referral is made to the LMHP and/or MD or APRN to see patient at that visit
- Advanced assessment, if indicated
- Education and referrals to address needs and barriers

Step 8a

Patient is interested in STAR Program.



~ or ~

Step 8b

Patient is NOT interested in STAR Program.



Step 7

Navigator forwards problem list to STAR coordinator for review and STAR screening referral. If patient checks any of the 14 rehab "triggers" on the Distress Screening Tool, nurse navigator educates patient about the STAR Program.

Step 5

Navigator's resource center has educational handouts that align with every problem in the NCCN problem list.



Step 6

Front desk staff scans distress screening form into patient's EHR.



CHALLENGES TO DISTRESS SCREENING

After the site visits, the project team identified the following challenges for distress screening. These challenges were observed across all three pilot sites.

- 1. Staffing.** Patient needs appear to overwhelm available support staff, yet additional staff may not be added, despite distress screening adding to clinical volume for supportive services. Sometimes trainees are used as extenders for permanent staff.
- 2. Multiple EHRs.** It was common to find multiple EHRs across a hospital system, and these EHRs often do not communicate with each other. For example, radiation oncology may use MOSAIQ®, while medical oncology uses Epic.
- 3. Funding.** Sometimes support services start with philanthropic funds, which are often not sustainable nor can they guarantee continuity of care over time. Efforts are made to move staffing positions to institutional funding, but this move can be difficult because support services are generally not billable.
- 4. Variability of methodology.** There is some variability across clinical services and among staff within a cancer center about how and when distress screening is administered, how staff is trained or oriented, how patients are educated about the screening, and how patients are informed about the response to a positive screen.
- 5. Process challenges.** Documentation may not be done until the end of the day, making it difficult to capture all relevant information. Without an electronic methodology for administering screening, staff has to enter the paper screening results into the EHR or scan the paper result into the EHR. All sites struggled with how to systematize re-assessment and how frequently to re-assess.
- 6. Target population.** Most distress screening focuses on outpatients; all sites struggled with how to screen inpatients.
- 7. Screening Tool.** Not all sites elected to use a validated instrument and not all sites used the evidence-based cut off scores, despite CoC recommendations and recommendations set forth by expert consensus to do so.²



KEY RECOMMENDATIONS

While challenges to distress screening have been documented, including resistance from medical providers, limited resources, or limited staff,¹⁰ this project identified three community cancer programs that have successfully implemented distress screening, yet with distinctly different procedures and structures. Upon observation and data collection, it was evident that these three programs were generally well endowed with resources, support staff, and institutional commitment. Providers at all three programs alluded to the fact that distress screening was not only a method of identifying high-risk patients but also a means to link patients with existing supportive care services and programs.

Our findings suggest that certain provider and institutional characteristics promote successful implementation of distress screening, including:

- An institutional commitment to distress screening and supportive care
- Staff training and understanding of their role in the distress screening process
- An identified point-person responsible for overseeing screening procedures
- Use of computerized systems, whether for documenting paper format or directly for screening, for linking patients to appropriate services based on their indicated needs.

We recommend these practices for cancer programs struggling with implementation of distress screening.

GOING FORWARD

Compliance with CoC Standard 3.2 will require that cancer programs provide evidence of the extent to which distress screening is occurring as prescribed and is responsive to patient needs. While our site visits detailed procedures and provided some data on percentages of patients being screened, we did not collect data to substantiate whether screening indeed resulted in appropriate follow-up and subsequent improvements in patient outcomes. In some instances, psychosocial contact and referral occurs as a part of day-to-day practice—absent distress screening. It will be important that cancer programs collect and examine their data for statistical trends indicating whether identifying distressed patients impacts clinical outcomes. In addition it will be important to track inequities in adherence or responsiveness with patients from marginalized or vulnerable groups (e.g., ethnic and racial minority patients, older patients, non-English speaking patients).

While the oncology community may believe that distress screening helps people obtain the assistance and support they need—and some empirical research indicates that increases in referrals to and utilization of psychosocial support services are indeed a function of distress screening—there is not yet evidence to support the assertion that distress screening and subsequent follow-up result in improved patient or institutional outcomes. Sustainability of distress screening will require data demonstrating the extent to which distress screening occurs as prescribed and indeed results in desired patient and institutional outcomes. Even though diversity in structures and processes was evident across the three cancer programs evaluated as part of this project, future research may be enhanced by establishing a typology of distress screening programs based on common components, such as frequency of screening, instrument used, or characteristics of EHRs. A typology of screening programs could perhaps be useful in comparing and isolating effectiveness of various distress screening models or components of a comprehensive distress screening process as they contribute to improved patient and institutional outcomes.

continued



The team acknowledges several project limitations, including a bias introduced by using items from the NCI instrument to select high-performing sites. The selection process intentionally favored programs with strong infrastructures, resources, and distress screening processes in place. Future observational studies could be used to learn how providers are successful in implementing distress screening in environments that do not benefit from substantial abundant resources or institutional commitment.

Given the data gathered and the lessons learned from the site visits discussed above, the project team proposes these four recommendations for evaluation of distress screening programs:

1. Observe distress screening practices, particularly in terms of how screening is done across clinical settings.
2. Collect data indicating that screening occurs as prescribed and that appropriate response to screening occurred, when clinically indicated.
3. Analyze data to identify groups at-risk for not being screened or for inadequate psychosocial assessment and follow-up.
4. Assess patient endpoints, as measuring patient outcomes and/or endpoints are necessary to determine best practices.

APOS WANTS YOU TO KNOW...

1. When considered as a component of and integrated into a program of psychosocial care for cancer patients and survivors, distress screening appears to have more meaning and clinical utility than when considered a “protocol.”
2. Distress screening can be one of multiple pathways for referring patients to psychosocial resources.
3. Ongoing education and feedback about distress screening and about resources for patients are essential—for providers and patients.
4. Distress screening is a process that evolves over time and—with careful monitoring and system feedback—can be adapted and improved to better suit the needs of the cancer program and its patients.



PROJECT & SURVEY METHODOLOGY

ELIGIBILITY CRITERIA

The team sought to ensure that the three sites selected for this project represented a diversity of settings and patient populations. Active ACCC membership and evidence of a well-functioning psychosocial distress screening program, as determined by survey responses and selection criteria, were baseline eligibility requirements. ACCC provided a list of candidate sites meeting these criteria. APOS also recommended a number of programs to add to this list. Using these baseline criteria, APOS designed a two-step selection process. ACCC retained the right to make the final determination of sites to visit.

SELECTION CRITERIA

The ACCC-APOS selection team designed selection criteria using an iterative, consensus process with input from all members. A brief survey comprised of two components was designed and approved. The first component consisted of nine questions representing yes/no answers based on CoC accreditation Standard 3.2 for Distress Screening. The answers to these questions elucidated organization structures (e.g., cancer committee psychosocial representation), screening instrument(s) and processes, documentation and referrals.

The second component used selected items from the NCI Community Cancer Center Program (NCCCP) Psychosocial Matrix.¹¹ This self-assessment tool examines program capacity to deliver psychosocial services and rates capacity in 7 domains at 5 levels. For this project, 3 domain items were used to evaluate capacity to:

1. Identify psychosocial needs of cancer survivors (defined as anyone diagnosed with cancer)
2. Design and implement a psychosocial care plan
3. Conduct follow-up and re-evaluation to adjust the care plan as needed.

ACCC distributed the survey to the candidate sites meeting eligibility criteria. In addition to the components discussed above, the team also collected demographic information, including the contact person at each site and his or her position at the cancer program. Twenty-seven sites met eligibility criteria and completed the two-part survey to evaluate their distress screening programs.

SELECTION OF PILOT SITES

Based on the data from the 27 initial participants, the APOS team rank-ordered eight high-scoring sites and recommended three pilot and two alternative sites based on consideration of survey scores, diversity of settings, and committee consensus. ACCC reviewed APOS recommendations and then selected three pilot sites from the recommended list. The selected sites agreed to a site visit by a subset of team members and the APOS team developed a site-visit plan. Prior to the visit, pilot sites were asked to provide the following data:

- A copy of their distress screening algorithm or protocol or institutional policy
- Cancer center analytic cases for the previous year
- Percentage of non-English-speaking patients
- Percentage of minority (race/ethnicity) patients.

For the site visit, the project team requested meetings with key leadership and salient personnel. Suggested staff included the psychosocial representative on the cancer committee, site-defined key staff, leaders of patient care or supportive care services, cancer

continued



center clinical director, and quality and/or compliance directors. These activities allowed the project team to examine the processes of care involving screening, documentation, and communication, as well as organizational support and leadership.

To ensure comparability across sites, the project team asked key leaders at each site a brief set of questions that focused on:

1. Establishment of the distress screening program
2. Processes of screening and psychosocial care
3. Quality measurement and communication.

Finally, the project team adapted the RE-AIM framework¹² to examine the following statement: “To assure compliance with the CoC standard, do you have evidence related to the following areas?” Areas evaluated included the reach and efficacy of distress screening, as well as documentation of discussions between provider and patient of results of screening, and documentation of results of screening program at the organizational level (i.e., cancer committee).

REFERENCES

1. Institute of Medicine. Cancer care for the whole patient: Meeting psychosocial health needs. In: Adler NE, Page AEK (eds.) Washington DC: The National Academies Press, 2008.
2. Pirl WF, Braun IM, Deshields TL, et al. Implementing Screening for Distress: The Joint Position Statement from the American Psychosocial Oncology Society, Association of Oncology Social Work, and Oncology Nursing Society. 2013. Available online at www.apos-society.org. Last accessed July 8, 2015.
3. Carlson LE, Waller A, Mitchell AJ. Screening for distress and unmet needs in patients with cancer: review and recommendations. *J Clin Oncol*. 2012;30: 1160-1177.
4. Bultz BD, Cummings GG, Grassi L, Travado L, Hoekstra-Weebers J, Watson M. 2013 President's Plenary International Psycho-oncology Society: embracing the IPOS standards as a means of enhancing comprehensive cancer care. *Psycho-oncol*. 2014;23: 1073-1078.
5. Andersen BL, DeRubeis RJ, Berman BS, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: An American Society of Clinical Oncology guidelines adaptation. *J Clin Oncol*. 2014; 32: 1605-19.
6. Lazenby M, Tan H, Pasacrete N, Ercolano E, McCorkle R. The five steps of comprehensive psychosocial distress screening. *Curr Oncol Rep*. 2015;17: 447.
7. Wagner LI, Spiegel D, Pearman T. Using the science of psychosocial care to implement the new American College of Surgeons Commission on Cancer distress screening standard. *J Natl Compr Canc Netw*. 2013;11: 214-221.
8. Andersen B, Thornton L, Shapiro C, et al. Biobehavioral, immune, and health benefits following recurrence for psychological intervention participants. *Clin Cancer Res*. 2010;16:3270-3278.
9. Giese Davis J, Collie K, Rancourt KMS. Decrease in depression symptoms is associated with longer survival in patients with metastatic breast cancer: a secondary analysis. *J Clin Oncol*. 2011; 29:413-420.
10. Williams K, Brothers B, Ryba M, Andersen B. Implementing evidence-based psychological treatments for cancer patients. *Psycho-oncol*. In press.
11. Forsythe LP, Rowland JH, Padgett L, et al. The cancer psychosocial care matrix: A community-derived evaluative tool for designing quality psychosocial cancer care delivery. *Psycho-oncol*. 2013; 22: 1953-62.
12. Dzawaltowski DA, Glasgow RE, Klesges LM, et al. RE-AIM: Evidence-based standards and a Web resource to improve translation of research into practice. *Ann Behav Med*. 2004; 28: 75-80.



ABOUT THE ASSOCIATION OF COMMUNITY CANCER CENTERS

The Association of Community Cancer Centers (ACCC) serves as the leading advocacy and education organization for the multidisciplinary cancer care team. Approximately 20,000 cancer care professionals from 2,000 hospitals and practices nationwide are affiliated with ACCC. Providing a national forum for addressing issues that affect community cancer programs, ACCC is recognized as the premier provider of resources for the entire oncology care team. Our members include medical and radiation oncologists, surgeons, cancer program administrators and medical directors, senior hospital executives, practice managers, pharmacists, oncology nurses, radiation therapists, social workers, and cancer program data managers. Not a member? Join today at accc-cancer.org/membership or email: membership@accc-cancer.org. For more information, visit the ACCC website at accc-cancer.org. Follow us on Facebook, Twitter, LinkedIn, and read our blog, ACCCBuzz.

©2015. Association of Community Cancer Centers. All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means without written permission.

Association of Community Cancer Centers

This publication is a benefit of membership.



11600 Nebel Street, Suite 201
Rockville, MD 20852
301.984.9496 • accc-cancer.org



PRACTICEPROFILES

Brought to you by the Association of Community Cancer Centers with funding and support provided by Pfizer