

# Using a Quality Improvement Model to Implement Distress Screening in a Community Cancer Setting

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## Abstract

**Background:** Quality cancer care includes routine screening for psychosocial distress. This quality improvement project focused on the implementation of distress screening at a licensed affiliate of Cancer Support Community, a community-based non-profit organization that provides professionally led cancer support. **Methods:** An advanced practice oncology nurse assisted the staff in implementing and evaluating the process of distress screening. CancerSupportSource (CSS), a validated web-based distress screening program developed by Cancer Support Community for use in community cancer settings, was employed to screen for distress, identify potential resources, and improve in-house and community referrals. For purposes of this quality improvement project, CSS was administered in interview format by staff. The Plan-Do-Study-Act (PDSA) quality improvement approach was used to implement CSS. **Results:** To implement the practice of distress screening, 21 patient participants were initially screened and evaluated for distress, including risk for clinically significant levels of depression, using CSS. The tool identified participant concerns and flagged thirteen persons as at risk for depression. After implementation and evaluation of distress screening using PDSA, in a year, 51 participants were screened. Participants stated that distress screening allowed for discussion of intimate questions that may not have otherwise occurred in an intake interview. **Conclusion:** It was demonstrated that CSS identified psychosocial and practical needs, facilitating the referral process and identification of community resources. Application of the PDSA model was an effective quality improvement model that can be used for the implementation and sustainability of distress screening across settings.

The journey on the cancer trajectory brings distress for patients and families, in part due to the threat of mortality and the unforeseen treatments that ensue. In the context of cancer, distress has been defined as an “unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (National Comprehensive Cancer Network [NCCN], 2020). The causes of distress are multifactorial and can occur at any point along the cancer continuum (diagnosis, treatment, end of treatment, recurrence, and end-of-life care) and may change over time (Cook, Salmon, Hayes, Byrne, & Fisher, 2018; Gao, Bennett, Stark, Murray, & Higginson, 2010). Distress can range from normal feelings of fear, vulnerability, and sadness, to more serious symptoms of “depression and anxiety, panic, social isolation, and existential and spiritual crisis” (NCCN, 2020). Research has found that patient distress is associated with reduced quality of life, poor response and adherence to treatment, poor self-management, higher health-care costs, and higher mortality (Estes & Karten, 2014; Fann, Ell, & Sharpe, 2012; Gao et al., 2010; Mehnert et al., 2017). Estimations state that one third to one half of patients receiving outpatient cancer care have symptoms of distress due to pain, fatigue, insomnia, and depression (Fann et al., 2012), and impaired mobility and cognition negatively affect survivors’ private, social, and work life in addition to activities of daily living (Mehnert et al., 2017). In a systematic review of the literature, baseline distress has consistently predicted longer-term distress over the cancer trajectory (Cook et al., 2018).

The Institute of Medicine’s (IOM) report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* (2008), outlined the deleterious effects of unmet psychosocial needs and identified the beneficial effects of providing psychosocial services to patients (Adler & Page, 2008; Jacobsen & Wagner, 2012). In addition, the IOM report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* (2013), stressed that patient-centered care must include emotional support to relieve fear and anxiety as well as ad-

dress mental health issues (Levit, Balogh, Nass, & Ganz, 2013). These seminal publications contributed to the burgeoning assessment of the psychosocial and psychological needs of patients with cancer at diagnosis and survivorship.

Given and Given (2015) outline assessment domains needed for psychosocial care, which include functional status, symptom severity, mental/cognitive status, emotional conditions, and social support/resources. Physical distress and psychosocial distress are interdependent (e.g., unmanaged pain can directly contribute to emotional states such as depression or anxiety). Therefore, distress has both physical and psychological attributes demanding holistic care of the patient. Distress has been identified as the sixth vital sign (Mitchell, 2015); however, the literature suggests that routine screening for distress is not universal across settings (Ehlers et al., 2018; Jacobsen & Wagner, 2012), and early distress is a significant predictor of ongoing or later distress (Girgis, Smith, & Durcinoska, 2018). Without adequate screening, many will suffer silently if effective interventions are unavailable to prevent the negative sequelae of distress. The American College of Surgeons Commission on Cancer—an accrediting body of hospitals—set standards for patient-centered care that require distress screening and appropriate referral for services (2016). Despite this recommendation, Jacobsen & Wagner (2012) stress that the wider community of oncology professionals may not be cognizant of these recommendations and changes in practice.

The primary purpose of this quality improvement (QI) project was to implement an innovative web-based tool to standardize distress screening at a licensed affiliate of Cancer Support Community (CSC), a community-based non-profit organization that provides professionally led cancer support. A secondary outcome was to improve referral and access to resources for a population of participants who experienced distress, including those who were identified as at risk for clinically significant depression. Distress screening has been acknowledged by professionals as a way to structure and streamline patient communication and provide insight into patient referral desires and needs, thus ensuring referrals that most correctly meet those needs (Girgis et al., 2018).

## DISTRESS INSTRUMENT

Research suggests that the use of informatics tools may improve a provider's ability to screen for symptoms such as psychosocial distress (Miller, Mullins, Onukwugha, Golant, & Buzaglo, 2014; Wagner et al., 2015). Although the use of informatics tools to assess for symptoms is growing across settings (Baer et al., 2013; McNeely et al., 2015), there are limited descriptions of self-administered tablets for symptom screening in oncology settings. Cancer Support Community created and evaluated CancerSupportSource (CSS), an innovative web-based program for distress screening that can be administered via Internet or tablet format (Buzaglo, Zaleta, McManus, Golant, & Miller, 2019; Miller et al., 2014). CancerSupportSource can be used to screen for psychosocial, physical, and practical distress in the person experiencing cancer. Psychometrically validated by CSC, it is implemented in their affiliate networks across the United States. Initially a 25-item distress screening tool, the CSS was validated by a cross-sectional survey of 251 cancer survivors (Miller et al., 2014).

In its current implementation within the CSC network of affiliates, a 15-item version of the scale was validated and used to assess cancer patient and survivor distress (Buzaglo, Miller, Golant, Longacre, & Kennedy, 2016). For each item, participants rate their level of concern (0 = not at all; 1 = slightly; 2 = moderately; 3 = seriously; 4 = very seriously). Items range from physical to psychosocial concerns and are outlined in Table 1. Scores on the 15 items are totaled to give a score out of 60. A staff/clinician "Distress Screening Report" delineates the participant's score for each individual item and lists the participant's top five concerns. The CSS distress screening is designed to be self-administered, taking an average of 5 to 7 minutes to complete. In this QI project, it was decided to incorporate the CSS into the prescribed intake interview to allow evaluation of distress screening administration and patient receptivity. Following its completion, the tool automatically generates a patient report, "My Support Care Plan," as well as the staff/clinician report. This plan includes a list of local services and Internet resources to address areas of concern identified by the participant. In addition, the care plan serves as an educational resource to be reviewed by the staff/clinician with

**Table 1. The CancerSupportSource Domains**

**Today, how CONCERNED are you about...**

Feeling irritable?
Sleep problems?
Changes or disruptions in work, school or home life?
Feeling sad or depressed? <sup>a</sup>
Pain and/or physical discomfort?
Body image and feelings about how you look?
Feeling nervous or afraid? <sup>a</sup>
Worrying about the future and what lies ahead?
Making a treatment decision?
Feeling lonely or isolated? <sup>a</sup>
Health insurance or money worries?
Feeling too tired to do the things you need or want to do? <sup>a</sup>
Worrying about family, children and/or friends?
Exercising and being physically active?
Finding meaning and purpose in life?

*Note.* <sup>a</sup>Risk for depression subscale.

the patient. The CSS can be used for rescreening to evaluate for changes in distress after the participant attends a support group, individual therapy, or other CSC activity.

CancerSupportSource also includes a depression risk screening subscale; the current study used a four-item version of the scale (see Table 1). Item discrimination for the subscale is addressed elsewhere (Buzaglo et al., 2016). Risk for depression was determined by summing the participant ratings of the four items; a total score greater than 5 indicates the participant is at risk for depression and additional evaluation is recommended. A flag will appear on the staff/clinician report and trigger an email to the Program Director and/or appropriate professional. When triggered, the staff/clinician will discuss the concerns with the participant, suggest sharing this information with his/her health-care team, and in this affiliate, refer the participant for six free individual sessions with a therapist at CSC. If the participant is assessed to need psychiatric intervention, immediate referral is warranted and provided. The flag does not prohibit the participant from referral to, or attendance at, CSC support programs at this affiliate.

## A QUALITY IMPROVEMENT FRAMEWORK: PLAN-DO-STUDY-ACT

To ensure a systematic approach to the implementation and evaluation of the CSS informatics tool, a Plan-Do-Study-Act (PDSA) QI framework was employed (see Figure 1). This framework is an effective method of supporting healthcare organizations to initiate change, reach quality goals, and structure improvement work (Crowl, Sharma, Sorge, & Sorensen, 2015). Three essential questions clarify the purpose of the improvement process, suggest measures to ascertain and evaluate the change, and identify the changes involved in the project. The initial question is, “What are we trying to accomplish?” The major goal of this QI project was to implement and evaluate the process of distress screening at a CSC affiliate where there was no baseline screening being carried out. The second question inquires, “How will we know if a change is an improvement?” If patients’ demonstrated receptivity and ease in completing the CSS tool, the “Act Phase” would readily evaluate the most effective process to incorporate the CSS distress screening in this setting. Finally, the PDSA process asks, “What changes can we make that will result in improvement?” This QI project pro-

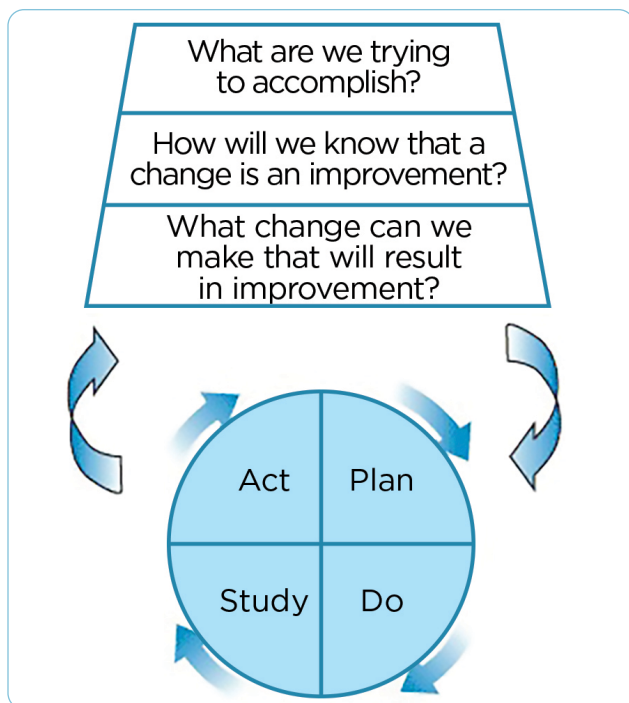
vided valuable information regarding the process of distress screening and provided a “jump-start” to implementation (Crowl et al., 2015).

Initially developed for business, this framework has been adapted by health care for use in quality improvement (QI) projects (Crowl et al., 2015; Riblet et al., 2014; Taylor et al., 2014). The Centers for Medicare and Medicaid Services (CMS) have promoted use of this model to bridge the gap between organizations implementing QI and identifying how to improve quality (Crowl et al., 2015). The PDSA is iterative; it allows for planning the change, implementing the change, observing and studying the results, then acting on what is learned. The PDSA model provided a roadmap for implementing distress screening in this community cancer setting.

## METHODS

### Planning Phase (Setting)

The planning phase began by answering the first question of the PDSA model, “What are we trying to accomplish, with whom and where?” The QI project took place at a CSC affiliate in a suburban Southern California neighborhood. Cancer Support Community is the largest nonprofit network of cancer supportive services worldwide. Participants receive information about CSC from health-care professionals in the community, mass media advertisements, and social media outlets. Patients coming to a CSC affiliate can participate in support groups, educational classes, and other types of interventions (e.g., yoga, journaling). Licensed marriage and family therapists (MFTs) or licensed social workers (LSWs) lead all support groups. The mission of CSC, including the affiliate for this project, is “dedication to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.” Programs at CSC are provided free of charge due to the generosity of local corporations, foundations, and individual donations. In this project, the CSC team identified stakeholders to coordinate the staff training, pilot the web-based tool, and evaluate the implementation process. One month before initiation of the project, staff received an email from the affiliate Director and Board of Directors to enhance overall support. California State University Long Beach



**Figure 1.** Model for improvement. From Norman et al. (2009). Used with permission.

Institutional Review Board provided review and approval of the project (administrative review 16-416). Verbal informed consent was obtained from all participants who were reminded of the option to stop participating in the CSS at any time. The confidential nature of personal data was assured.

### **Do Phase (Intervention)**

All participants interested in joining this CSC affiliate attend an orientation program and a brief intake interview. Affiliates also have the option to record demographic and clinical information (e.g., disease state, stage, and treatment) that was obtained at this time. Distress screening was conducted during the beginning of the intake interview after explanation of the project was provided. Patients were informed that participation and completion of the CSS was voluntary and oral consent was obtained. If a patient declined to participate, they were informed that the open-ended intake interview would proceed as usual. Thirty to forty-five minutes was normally allotted for the intake interview; on average, a minimum of 1 hour was needed when combined with the CSS to allow for QI program explanation. When self-administered, the CSS takes only 5 to 7 minutes but when carried out in the presence of the screener who inputted participants' responses into the tablet, patients frequently stopped and expressed emotions with respect to questions from the tool. The staff member conducting screening provided immediate support and made appropriate referrals if needed.

Staff members (e.g., MFT interns and LSW interns) were also educated to employ the screening process due to the objective of sustainability for the program. Staff training consisted of observing two CSS screenings with the primary author and carrying out debriefing sessions afterwards. The debriefing sessions provided an opportunity to answer staff questions, review documentation procedures, and ensure confidentiality. In addition, all intern staff were required to complete an online training program with the CSS software vendor prior to implementing the screening tool.

### **Study Phase (Analysis)**

The CSC affiliate allowed for deidentified CSS data to be accessed for the study phase. The following

descriptive data were analyzed: 1) demographics of the program participants; 2) total distress scores; 3) depression risk scores; 4) most strongly endorsed concerns; and 5) referrals of at-risk participants. The study phase also included questions related to the screening process (e.g., "Was time allotment appropriate if CSS was incorporated into the intake interview using the tablet?" and "Could CSS distress screening take the place of the intake interview?").

Most participants were White, English speaking, employed full time, married/partnered, and college educated. Although breast cancer was the predominant diagnosis ( $n = 11$ ), other diagnoses included ovarian, endometrial, central nervous system/brain, lung, prostate, colorectal, and non-melanoma skin cancer. Demographics are provided in Table 2.

Total distress scores ranged from 3 to 51 out of a possible 60 (mean: 22.14, standard deviation: 13.19). Based on both severe distress ( $> 40$ ) and at-risk depression scores ( $> 5$ ), two participants received definitive referrals to appropriate psychiatrists in the community and were offered individual therapeutic sessions with a CSC therapist. Thirteen participants (62%) answered moderate to very seriously (three or above) to at least one of the following four concerns comprising the depression risk subscale: feeling sad or depressed, feeling nervous or afraid, feeling lonely or isolated, and feeling too tired to do the things you need or want to do. Scores across these four items were totaled and if greater than 5, the individual was identified as "at risk for clinically significant depression" (38% of participants screened). These participants received referrals for individual therapy at CSC and were recommended for psychotherapy in the community.

A major concern for the majority of participants was fatigue (feeling too tired to do the things you need or want to do; 72%) along with concern about exercising and being physically active (62%). Half or more of the participants also identified moderate to very serious concern about sleep problems (52%), irritability (50%), worries about the future and what lies ahead (57%), changes or disruptions in work, school or home life (52%), feeling sad or depressed (57%), body image and feelings about how they look (57%), health insur-

**Table 2. Demographic Sample Characteristics (N = 21)**

Characteristic	No.
Age range (average age: 62.04; SD: 12.53)	
38-60	11
60-82	10
Gender	
Female	17
Male	4
Cancer diagnosis	
Breast	11
Ovarian	3
Endometrial	1
CNS/brain	1
Lung	2
Prostate	1
Colorectal	1
Skin (non-melanoma)	1
Stage of cancer	
Stage 1	3
Stage 2	8
Stage 3	2
Stage 4	7
Don't know	1
Length of time since diagnosis range	
Less than 1 year	12
Greater than 1 year	9
Active treatment	
Yes	13
No	8
Education	
High school	2
Some college	5
College	8
Graduate	5
Prefer not to share	1
Ethnicity	
White	16
Latino	2
Native American	1
Other	2

Note. SD = standard deviation; CNS = central nervous system.

ance or money worries (50%), and worrying about family, children, and/or friends (52%). Forty-three percent (n = 9) of participants reported moderate to very serious concern about pain or discomfort, consistent with other research suggesting that up to one half of patients receiving outpatient cancer care are affected by pain, increasing as the disease

**Table 2. Demographic Sample Characteristics (N = 21) (cont.)**

Characteristic	No.
Marital status	
Single	2
Partnered	1
Married	10
Live with significant other	2
Divorced	3
Widowed	3
Living situation	
Spouse or significant other	13
Live alone	3
With children under 18	3
With children over 18	2
Employment	
Part time	2
Full time	12
Homemaker	1
Retired	6
Income range	
Less than \$20,000	1
\$20,000-\$39,999	2
\$40,000-\$59,999	2
\$80,000-\$99,999	2
More than \$100,000	5
No disclosure	6
Don't know	3
Health insurance	
Yes	20
No	1

Note. SD = standard deviation; CNS = central nervous system.

enters more advanced stages (Fann et al., 2012). Four patients reported moderate to very serious concern about finding meaning or purpose in life. All participants who completed the CSS were assigned to a support group within the CSC and were informed of other CSC resources available to them such as yoga or journaling class. For those participants with significant reports of symptoms such as fatigue or sleep, group therapists received the clinician report, "Distress Screening Report," to assist them in individualizing support to the identified needs of the participant.

### Act Phase (Discussion)

The final phase of PDSA is to review the process and make modifications for improvement, in this case distress screening, and then repeat the cycle.

Discussion during the Act phase of PDSA answers the second question, “How will we know if a change was an improvement?” The ability to evaluate the immediate effectiveness of distress screening proved successful. All participants approached were receptive to completing the CSS tool. The CSS tool asks, “Did you find this survey to be helpful?” The majority of respondents answered yes to this question (18 = yes; 3 = no [2 males; 1 female]). It is also important to consider the patient perspective when evaluating the effectiveness of distress screening (Chiang, Amport, Corjulo, Harvey, & McCorkle, 2015; Faller et al., 2016; Fromme et al., 2016). After screening, each participant received a minimum of one email or phone call to assess if they had attended a support group or other activity and if those referred for psychotherapy had accessed that referral. Each participant had attended either a support program and/or other CSC activity, e.g., yoga. One patient referred for follow-up psychiatric evaluation had sought care. In addition, participants had the opportunity to be rescreened for distress 1 month after baseline. Only three participants responded to the email invitations for rescreening.

The third question of the PDSA model, “What changes can we make that will result in improvement?” was evident. For program sustainability, approaches to optimize follow-up with participants were identified as necessary. With respect to the low response rate to follow-up screening invitations, future research should explore benefits and barriers to completing follow-up, including optimal time intervals between initial and follow-up screening(s). This would consist of repeating CSS for reassessment at 1 to 3 months if the participant experienced a triggering event (e.g., recurrence) or at a longer interval for others (e.g., 3 or 6 months). Zebrack and colleagues (2015) stress the necessity of systematic tracking of clinical responses to distress screening. This tracking provides the necessary data to demonstrate the effectiveness of an institution’s ability to address psychosocial needs associated with cancer.

Reassessment would also identify exactly which CSC and community resources were utilized over time. Staff buy-in for the screening process was an ongoing challenge: new staff members were more receptive to being trained to integrate

the screening process than seasoned staff. Responsiveness is seen as improving as clinical staff are educated on the intent and complexities of screening and are given ongoing feedback regarding the benefits for patients and quality care (Zebrack et al., 2015). Future interventions to consider include carrying out routine training sessions for MFTs and LSWs and incentivizing senior staff by asking them to oversee the distress screening program in the future. Evaluating how individual therapists leading support groups could apply the information gained via distress screening was identified as another future endeavor. Although therapists genuinely supported the idea of distress screening, the majority did not readily include the information gained into treatment planning for new participants joining support groups. The continued support of CSC Board Members for distress screening was also seen as vital for program sustainability; therefore, pre- and post-QI information was consistently shared by the program director. The CSS has now become a standard of care at this CSC affiliate and the majority of incoming patients (> 51) were screened in the year following the QI process. Additional recommendations that follow have further implications for practice.

## IMPLICATIONS FOR PRACTICE

The CSC introduced the CSS distress screening program as an evidence-based, standardized approach to identify and mitigate distress among cancer survivors. This project identified the effectiveness of the CSS for distress screening. Prior to tool implementation at this setting, participants at risk for depression may not have been readily identified and may have not received referral for further evaluation of distress. This CSC affiliate chose to implement the CSS during the customary intake interview, yet time and staff resources may not always be available for such intensive assessment. If the CSS is implemented in a setting that has limited time for intake, the individual can answer the screening questions on the tablet by themselves and the professional can then review the results with them, providing the needed resources. In addition, the CSS can be emailed to the participant prior to the intake interview in busy clinics or office settings. The CSS has proven to be adaptable dependent upon the needs of indi-

vidual patients and settings (Buzaglo et al., 2019). Variability does exist in the tools used for distress screening; therefore, it is important for health-care providers to choose those measures that are most appropriate for their specific settings, patients, and anticipated process of screening (Ehlers et al., 2018).

Sufficient referral and support services also influence the success of distress screening programs (Biddle et al., 2016). As the distress screening mandate requires a referral mechanism, it is imperative that a tool can detect those at risk for mental health issues such as anxiety and depression (Buzaglo et al., 2019; Ehlers et al., 2018). This CSC setting offers support groups for all participants and individual counseling for participants at risk for depression. In addition, the CSS provides the “My Support Care Plan,” which lists vital written informational resources as well as online and community resources available to the participant. A community referral list of additional resources ranging from physical, practical, to therapeutic support services was developed prior to tool implementation so that screeners could feel confident with referring patients appropriately if needed.

Although the focus of the screening was to identify distress, all the participants expressed the value of sharing their cancer journey in a safe and unhurried manner. Application of a distress tool such as the CSS allows intimate questions and discussion from the participant that may not otherwise have been discussed in a customary intake interview or consultation (Brandes, Linn, Smit, & van Weert, 2015). Adequate training of the professionals implementing distress screening is vital to the success of distress screening programs (Brandes et al., 2015). Training clinicians to be comfortable with the intimacy of the questions is imperative. If the clinician feels ill-equipped with dealing with certain questions (e.g., “Worrying about the future and what lies ahead”), participants may feel limited in discussing their concerns (Biddle et al., 2016, p. 64). Distress screening does not diagnose but is part of a stepped care model to differentiate between those who benefit from typical support resources and those who need referral for evaluation of more intensive services (Lazenby, Tan, Pasacreta, Ercolano, & McCorkle, 2015). In a stepped care model, staff can be trained to provide

low-intensity interventions that are delivered via written materials or information technology with limited professional guidance (Granek, Nakash, Ariad, Shapira, & Ben-David, 2019).

## LIMITATIONS

The goal of this QI project precludes generalizability. The small homogenous sample (most were White, female, married, educated, and employed outside the home) limits generalizability to more diverse communities. In addition, all participants were self-selected patients seeking psychological support at CSC. Challenges for distress screening in this setting remain similar to those reported in the literature: the time allotted for distress screening by staff and limited resources of trained staff available (Groff, Holroyd-Leduc, White, & Bultz, 2018). Utilizing the CSS via self-administration could serve to minimize these obstacles. Finally, incorporating the CSS during the intake interview may not prove feasible for program sustainability.

The PDSA QI approach was followed to implement the CSS tool into practice and proved valuable as a resource for evaluation and repetition of the cycle. The benefits of implementation were similar to recent research findings: enhanced communication, psychosocial referrals, and additional resources to improve patient well-being (Groff et al., 2018). Completing the CSS distress screening tool raised awareness of psychosocial, physical, and practical needs of participants and identified those at risk for distress. Future research should focus on the value and optimal implementation of follow-up screening and identification of resources utilized both at the CSC and in the community after initial screening. Evaluation of distress screening and follow-up in participants with poor prognoses are also needed. Lastly, implementation of the CSS as a self-administered tool is recommended.

## CONCLUSION

In this QI project, CSS was beneficial as a tool that met both the needs of identifying at-risk participants and providing referral resources needed both at CSC and in the community. Oncology advanced practitioners serve a pivotal role in leading QI projects to mitigate the distress that frequently results from receiving a cancer diagnosis and treat-



ment. The use of an innovative distress screening program, CSS, proved effective at identifying psychosocial needs of participants coming to the CSC affiliate. This project suggests that the extent of distress experienced in a sample of cancer survivors is significant and warrants a systematic approach to screening and referral in the community setting. ●

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### Disclosure

The authors have no conflicts of interest to disclose.

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