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Symptom Management and Supportive Care

Implementation of the Edmonton Symptom Assessment System for Symptom Distress Screening at a Community Cancer Center: A Pilot Program

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Key Words. Health plan implementation • Mass screening • Neoplasms • Palliative care • Psychological stress • Symptom assessment

Abstract

Background. Distress screening is mandated by the American College of Surgeons Commission on Cancer; however, there is limited literature on its impact in actual practice. We examined the impact of a pilot distress screening program on access to psychosocial care.

Methods. Edmonton Symptom Assessment System (ESAS) screening was routinely conducted at our community-based medical oncology program. Patients who screened positive for severe distress were sent to a social worker for triage and referred to the appropriate services if indicated. We compared the proportion of patients who had ESAS completed, the proportion of patients who screened positive, and the number of patients who had social work assessment and palliative care consultation over the preimplementation (September 2015), training (October/November 2015), and postimplementation (December 2015) periods.

Results. A total of 379, 328, and 465 cancer patients were included in the preimplementation, training, and postimplementation periods, respectively. The proportion of patients who completed ESAS increased over time (83% vs. 91% vs. 96%). Among the patients who had completed ESAS, between 11% and 13% were positive for severe distress, which remained stable over the three periods. We observed a significant increase in social work referrals for psychosocial assessment (21% vs. 71% vs. 79%). There was also a trend towards an increased number of palliative care referrals (12% vs. 20% vs. 28%).

Conclusion. Our community-based cancer center implemented distress screening rapidly in a resource-limited setting, with a notable increase in symptom documentation and psychosocial referral. ***The Oncologist*** 2017;22:995–1001

Implications for Practice: The American College of Surgeons Commission on Cancer mandates distress screening; however, there is limited literature on how this process should be implemented and its impact on clinical practice. We used the Edmonton Symptom Assessment System for routine symptom distress screening in a community-based medical oncology program that provides care for an underserved population. Comparing before and after program implementation, we found an increase in the number of documentations of symptom burden and an increase in psychosocial referrals. Findings from this study may inform the implementation of routine symptom distress screening in cancer patients.

Introduction

Patients with cancer frequently report multiple symptoms as a result of their cancer, cancer treatments, complications, comorbidities, and psychosocial stressors [1]. Fatigue, pain, anxiety, depression, anorexia, cachexia, dyspnea, and nausea represent some of the common symptoms among cancer patients [2]. A high symptom burden can negatively impact patients' quality of life and function and is associated with poorer survival [3, 4].

To manage symptoms effectively, routine symptom screening is an essential first step. Regular assessments with validated questionnaires allow symptoms to be detected, diagnosed, treated, and monitored over time [5]. Recognizing the importance of routine symptom assessment, the American College of Surgeons Commission on Cancer (CoC) mandated psychosocial distress screening as a criterion for accreditation in 2015 [6].

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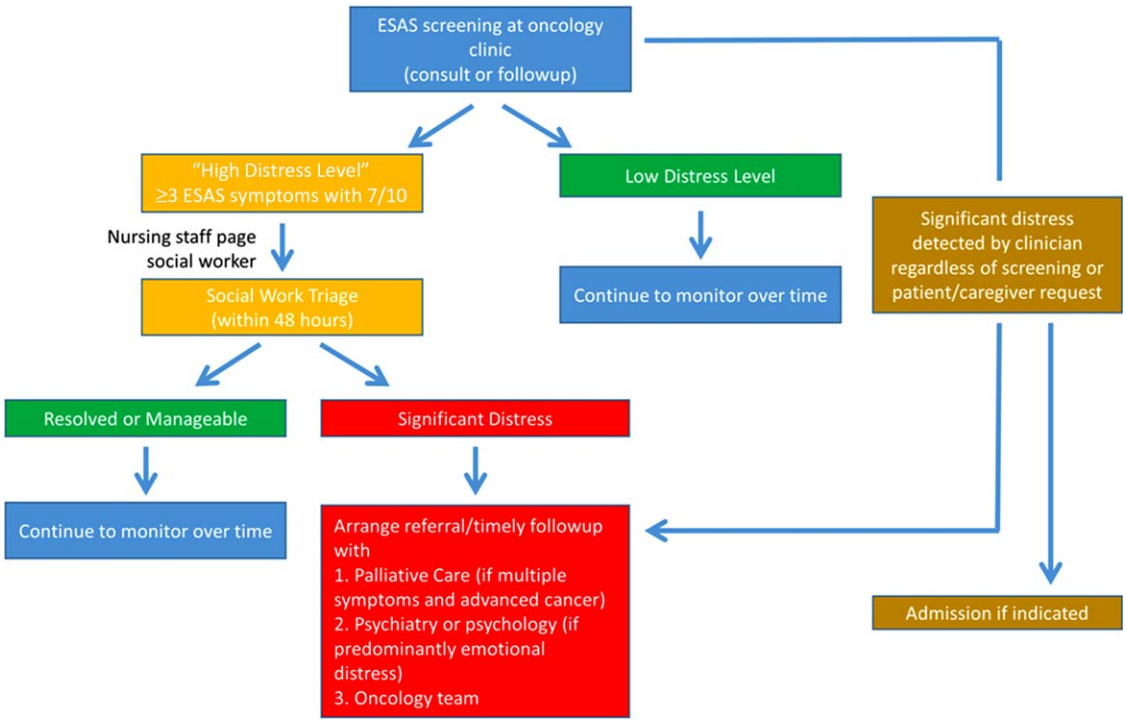

Figure 1. Blueprint for symptom distress screening at the General Medical Oncology Outpatient Clinic at Lyndon B. Johnson Hospital. Abbreviations: ESAS, Edmonton Symptom Assessment System.

Specifically, Standard 3.2 provides general guidance on five key aspects of distress screening, including the timing of screening, method, tools, assessment and referral, and documentation [7]. Multiple professional organizations, such as the National Comprehensive Cancer Network and the American Society of Clinical Oncology, have published clinical practice guidelines on distress screening [8–11].

Because psychological distress is often closely related to physical distress, questionnaires that can efficiently screen both domains may be particularly advantageous [10, 12]. The Edmonton Symptom Assessment System (ESAS) is a validated symptom battery that assesses 10 common physical and emotional symptoms using 11-point numeric rating scales that range from 0 (no symptom) to 10 (worst possible) [13]. It has been psychometrically and linguistically validated in over 20 languages and used extensively in both clinical and research settings in multiple countries worldwide [14–16]. For example, ESAS is endorsed by a pan-Canadian guideline for distress screening, which has been implemented in a province-wide manner in Ontario [10, 17].

Importantly, routine symptom screening needs to be coupled with regular evaluation, appropriate referral, and careful follow-up to have a meaningful impact [18]. To date, only a few studies have reported the experience of symptom distress screening with ESAS and associated outcomes [19–21]. A better understanding of how ESAS can be used for distress screening may facilitate its use to improve patient care. In 2015, the General Medical Oncology Outpatient Clinic at Lyndon B. Johnson (LBJ) Hospital implemented a pilot project with ESAS for distress screening. We examined the impact of ESAS screening on access to psychosocial care before and after program implementation at our community cancer center.

Materials and Methods

Participants and Setting

This quality improvement project was reviewed by the Quality Review Council at Harris Health and approved with waiver of informed consent. It consists of three phases: preimplementation in September 2015, training in October and November 2015, and postimplementation in December 2015. This study included consecutive patients seen at the General Medical Oncology Outpatient Clinic at LBJ Hospital during each of the three phases.

LBJ Hospital is a 328-licensed bed acute care facility that focuses on providing healthcare to medically underserved patients in Harris County, Texas, USA. The General Medical Oncology Clinic, accredited by the American College of Surgeons, operates every Monday, Wednesday, and Friday, with a survivorship clinic every Thursday. It is staffed by a rotating team of eight attending oncologists and 19 medical oncology fellows from the University of Texas MD Anderson Cancer Center, with on-site access to a social worker, a chaplain, and psychiatry and palliative care. In 2015, the program had approximately 500 new consultations and 9,500 total patient visits. Fifty-two percent of patients were actively receiving systemic therapy in this clinic.

Program Design and Implementation

A steering committee was formed to oversee the implementation for distress screening. It consisted of representatives from medical oncology, social work, case management, clinical nursing, and palliative care. A blueprint was designed based on CoC standards and existing guidelines, tailored to our county hospital setting (Fig. 1) [7]. ESAS was chosen as a screening tool over

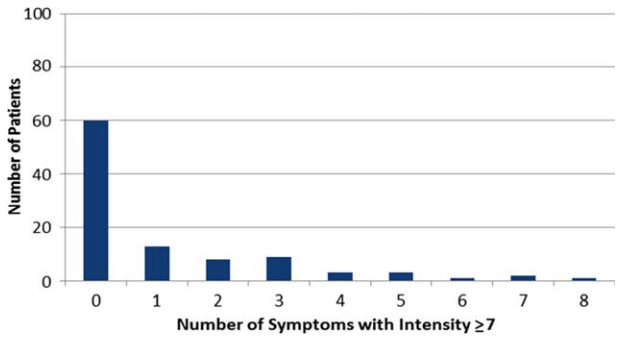

Figure 2. Symptom intensity by Edmonton Symptom Assessment System. Nineteen of 100 (19%) patients had at least three of eight target symptoms (pain, dyspnea, nausea, fatigue, anorexia, drowsiness, anxiety, and depression) with an intensity of 7 or higher. This was used as a cutoff for social work referral.

other validated tools such as the distress thermometer because it assesses multiple common physical symptoms in addition to psychological concerns. This pilot program was only implemented on Mondays and Wednesdays because no extra staffing resource was provided. Recognizing the lack of a consensus cutoff to trigger clinical action, the steering committee reviewed the ESAS symptom intensity for 100 consecutive patients seen at the oncology clinic in August 2015 and decided on an acceptable cutoff based on the literature and local resource availability. Among the 100 consecutive patients seen in August, the average ESAS symptom intensity was 2.7 for pain, 3.4 for fatigue, 1.2 for nausea, 1.9 for depression, 1.7 for anxiety, 2.1 for drowsiness, 1.8 for appetite, 2.8 for well-being, 2.1 for dyspnea, and 3.3 for sleep. Upon review of the distribution of patients with severe symptom distress (Fig. 2), the steering committee decided that patients with three or more out of the eight target (i.e., six physical and two emotional) symptoms with an intensity of 7 or higher should be further assessed. Nineteen out of 100 (19%) patients met this criterion. This threshold was set for the pilot based on the literature suggesting that an ESAS score of 7 has a high specificity for severe symptom distress [22] and is supported by a recent international consensus for outpatient palliative care referral criteria [23].

A preimplementation phase was engineered to understand the baseline level of symptom distress among our patients and to facilitate a before-and-after comparison of program implementation. During this time, ESAS data was routinely collected in September 2015 but not the rest of the distress screening program (Fig. 1). All patients at consultation or follow-up were given a paper copy of ESAS (English on one side and Spanish on the other) immediately after they checked in to the oncology clinic. ESAS has been validated in both languages, and patients may choose to complete either version. They were asked to rate the intensity of 10 symptoms "now," each with an 11-point numerical rating scale that ranges from 0 (no symptom) to 10 (worst intensity). For the purpose of distress screening, we focused on eight target symptoms, including six physical symptoms (pain, fatigue, nausea, drowsiness, shortness of breath, and appetite) and two emotional symptoms (depression and anxiety). The other two items were not included because wellbeing is an overall assessment, and sleep is an optional item in ESAS.

During the training phase, all clinic nursing staff had a 15-minute orientation to review the distress screening process (Fig. 1). Members of the steering committee were also available to answer any questions related to this project. Nursing assistants were responsible for administering ESAS on paper routinely and for reviewing the scores immediately after completion. Patients who met the predefined criterion were then referred to a social worker for triaging by the clinic nurses, who contacted the patients either in person during the same clinic visit or by telephone within 48 hours. The social worker focused on confirming that patient had severe symptom burden, conducted a psychological assessment, and provided counseling if appropriate. Patients were also given information on local resources and services. Those who remained in distress (e.g., severe pain or dyspnea) were referred to the appropriate services (e.g., palliative, psychiatric, or psychological care). During the training phase, key members of the steering committee, including the social worker, had weekly face-to-face meetings to ensure the proper procedures for screening and triaging were followed. We also audited the charts of consecutive patients on ESAS documentation and clinical actions taken and provided feedback to staff to strengthen the process.

During the postimplementation phase, the steering committee continued to reinforce the importance of this program and provided monitoring of the completeness of ESAS documentation, distress levels, and clinical actions.

Throughout the entire study, the oncology team had access to ESAS during the same clinic visit and would address the patient's concerns as per standard of care. The triaging and referral processes were built on the existing oncology practice to complement instead of replace routine care.

Data Collection

We collected data on consecutive patients during each of the three study phases, each lasting for 4 weeks. Preimplementation data were collected between September 2 and 30, 2015; training data were collected between October 21, 2015, and November 9, 2015; and postimplementation data were collected between November 30, 2015, and December 23, 2015. Baseline patient demographics, including age, sex, race, cancer diagnosis, and cancer stage were retrieved retrospectively. ESAS symptom data were captured prospectively during all three phases. We also examined the psychosocial referral pattern and documented the reasons for lack of clinical action during the training and postimplementation phases.

Statistical Analyses

We summarized the patient characteristics with descriptive statistics, including means and ranges. Our primary outcome was number of patients referred to social work and palliative care, which were the two key psychosocial services available at our institution. Secondary outcomes included the proportion of patients who had ESAS completed and the proportion of patients who screened "positive" (i.e., met the predefined criterion for social work triage). These outcomes were compared among the preimplementation, training, and postimplementation phases using the chi-square test or Fisher's exact test where applicable.

The Stata software (version 12.1, StataCorp LP, College Station, Texas) was used for statistical analysis. *A p* value of $<.05$ was considered significant.

Table 1. Patient characteristics

Patient description	Preimplementation $n = 379$ (%)	Training $n = 328$ (%)	Postimplementation $n = 465$ (%)
Age in years, average (range)	55 (21–86)	55 (20–94)	55 (19–87)
Female sex	221 (58)	183 (56)	265 (57)
Race			
White	53 (14)	37 (11)	62 (13)
Black	101 (27)	89 (27)	126 (27)
Hispanic	205 (54)	174 (53)	248 (53)
Asian	17 (5)	20 (6)	21 (5)
Others	3 (1)	8 (2)	8 (2)
Cancer diagnosis			
Breast	114 (30)	103 (31)	140 (30)
Gastrointestinal	115 (30)	93 (28)	135 (29)
Genitourinary	36 (9)	41 (13)	45 (10)
Head and neck	16 (4)	15 (5)	37 (8)
Hematological	34 (9)	20 (6)	32 (7)
Other	26 (7)	26 (8)	30 (6)
Respiratory	38 (10)	30 (9)	46 (10)
Stage			
0	7 (2)	3 (1)	6 (1)
I	41 (11)	38 (12)	51 (11)
II	72 (19)	69 (21)	85 (18)
III	105 (28)	71 (22)	115 (25)
IV	126 (33)	114 (35)	185 (42)
Pending	28 (7)	33 (10)	23 (5)

Table 2. Project outcomes

Screening	Preimplementation *n* (%)	Training *n* (%)	Postimplementation *n* (%)	*p* value[a]
ESAS completed	316/379 (83)	299/328 (91)	447/465 (96)	<.001
Severe symptom distress	34/316 (11)	35/299 (12)	58/447 (13)	.64
Social work referral[b]	7/34 (21)	25/35 (71)	46/58 (79)	<.001
Palliative care referral[b]	4/34 (12)	7/35 (20)	15/58 (28)	.21
Hospice care referral[b]	0/34 (0)	2/35 (6)	2/58 (6)	.54
Psychiatry or psychology referral[b]	3/34 (9)	2/35 (6)	4/58 (7)	.82

[a]Chi-squared test or Fisher's exact tests where appropriate.
[b]Among patients who met the criteria for severe symptom distress. One patient in the postimplementation group had both a palliative care and psychiatry referral.
Abbreviations: ESAS, Edmonton Symptom Assessment System.

Results

Patient Characteristics

Three hundred seventy-nine, 328, and 465 patients were included in the preimplementation, training, and postimplementation phase, respectively. As shown in Table 1, a majority were female and of Hispanic origin. Breast and gastrointestinal malignancies were the most common diagnoses. A majority of patients had advanced disease (stage III or IV).

Screening Program Outcomes

As shown in Table 2, the proportion of patients who completed ESAS increased over time ($p < .001$). We did not detect any significant differences in the ESAS completion rate between Hispanics and non-Hispanics in the preimplementation (84% vs. 83%, $p = .80$), training (90% vs. 93%, $p = 0.31$), and postimplementation phase (96% vs. 96%, $p = .85$). Among the patients who had ESAS completed, between 11% and 13% of them met the predefined criteria for social work triage, which remained stable over the three project phases ($p = .64$).

Among patients who screened positive for severe distress, we observed a significant increase in social work referral for further psychosocial assessment (21% vs. 71% vs. 79%, $p < .001$). There was also an increased number of palliative care referrals, albeit not statistically significant (12% vs. 20% vs. 28%, $p = .21$).

Table 3. Social work triage for patients with a positive screen

Action	Training $n = 25$ (%)	Postimplementation $n = 46$ (%)	Combined $n = 71$ (%)
Unable to contact patient	10 (40)	13 (28)	23 (32)
Patient contacted but did not want to discuss further	1 (4)	0	1 (1)
Patient contacted but denied having high symptom burden	0	0	0
Patient contacted but declined to be referred despite high symptom burden	0	3 (7)	3 (4)
Patient's concerns addressed by oncology team already	3 (12)	10 (22)	13 (18)
Patient referred to palliative care, psychiatry or psychology	9 (36)	18 (41)	27 (38)
Patient referred to hospice care	2 (8)	2 (4)	4 (6)

Table 3 provides more details about the triage process. Among the patients who screened positive for severe distress and triggered a social worker consultation, approximately 30% of patients could not be contacted and 20% already had their concerns addressed by their oncologists. No patient denied having a high symptom burden. Among the remaining patients who had significant distress, a palliative care referral was arranged.

Discussion

Our community oncology program was able to implement symptom distress screening coupled with psychosocial assessment/referral within a few months. In a before–after comparison, we observed an increase in the proportion of patients who had symptom burden documented by ESAS and a significant increase in the proportion of patients who received psychosocial assessment with a social worker. There was also a nonstatistically significant increase in the number of patients referred to palliative care. Our experience supports the feasibility of symptom distress screening in a resource-limited setting and provides us with further insights to refine this process at our center.

Several aspects of our distress screening program warrant discussion. Through orientation, education, and feedback, clinical staff were able to incorporate ESAS in their practice rapidly and demonstrated increased adherence to administering these questionnaires at every patient visit. In the postimplementation phase, a vast majority (96%) of patients had their ESAS completed, suggesting that it was feasible to screen with ESAS in the general oncology setting, despite the busy clinic flow and variable literacy level among our patients. In Canada, the province of Ontario implemented routine ESAS screening for ambulatory patients seen at regional cancer centers and reported a completion rate of between 70% and 90% [17]. Indeed, a recent systematic review on criteria for outpatient palliative care referral found ESAS to be the most commonly used tool for symptom screening [24].

The ability of ESAS to quantify multiple symptoms systematically and efficiently, coupled with its reliability, validity, and interpretability, makes it an ideal tool for routine screening in the oncology setting [25–33]. Cancer Care Ontario has implemented ESAS screening in multiple regional cancer centers since 2006, with over 2 million data points collected from 280,000 patients by 2014 [34]. Both patients and health care professionals perceived ESAS screening to be useful [35, 36]. However, an audit revealed that downstream clinical actions were only documented in the charts of 6% of patients with moderate-to-severe dyspnea and 29% of patients with moderate-to-severe pain, suggesting the need to reinforce management plans [37]. To date, only a handful of studies have examined how routine screening impacts clinical outcomes [38]. Bultz et al. reported that ESAS distress screening was associated with improved wellbeing and fewer physical, emotional, and practical problems in a before–after comparison [19]. Strasser et al. also found that patients had lower symptom distress when ESAS scores were routinely communicated with the oncology team compared to when they were not communicated [20]. Because few studies have published their experience in actual clinical practice and the associated outcomes [21], our study helps to address a significant gap in the literature.

One important aspect of distress screening is to define the cutoff to trigger further clinical action. Bagha et al. reported that cutoffs of $\geq$3 for ESAS depression and $\geq$2 for ESAS anxiety had high sensitivity but low specificity for distress screening [39]. Howell et al. proposed patients with a depression score of $\geq$4/10 or higher should be further assessed [10]. In a before-and-after implementation analysis, Bultz et al. reported their experience using ESAS cutoffs of $\geq$4 or higher [19]. Funk et al. used an ESAS cutoff of 8 or higher on at least one symptom scale as a trigger [21]. A higher threshold would have a greater specificity at the expense of lower sensitivity, and vice versa. We selected a highly stringent cutoff (i.e., three or more symptoms with intensity of $\geq$7/10) because (a) the literature consistently found that ESAS $\geq$7 indicates severe symptom distress [40], and (b) a lower threshold would overwhelm our sole social worker's capacity in this pilot project (e.g., 40% of patients had at least one symptom of $\geq$7). More recently, a Delphi study identified a high level of consensus among international experts that any severe physical, emotional, or existential distress (i.e., ESAS $\geq$7/10) may be appropriate to trigger a palliative care referral; however, it also emphasized that these recommendations need to be tailored to the local resources [23].

Our study provides real-life data for actual practice in a community oncology setting focusing on an underserved population. Because patients with a lower socioeconomic status were often less likely to report their symptoms, routine screening is particularly important [41]. Although our program had a high ESAS documentation rate, approximately 20% of patients who screened positive did not undergo a social work assessment, either because the social worker was not notified by the clinic nurses or because she was unavailable to conduct

screening within the 48-hour time frame. System-based features such as electronic alerts may reduce the miss rate. The inability for our social worker to contact 30% of referred patients represents another challenge. An in-clinic triage may help mitigate this issue. Finally, only 61% (27/44) of patients confirmed to be in distress by our social worker were referred to palliative care, which was consistent with the uptake rate in a recent systematic review [42]. Successful implementation of distress screening necessitates buy-in from the interdisciplinary team (e.g., nursing, oncologists, social workers, palliative care providers) to put it into action, longitudinal communication and education for the clinical staff, impeccable communication with patients and families, and regular audits to monitor progress [43].

Despite the above challenges, implementation of the distress screening program was associated with a significant increase in the number of patients who assessed psychosocial care in a before–after comparison. Our study period was relatively short, and there were no other significant program changes that likely contributed to this increase. Thus, we believe our findings are robust. In addition, routine screening may potentially augment oncology practice by enhancing oncologists' awareness to patients' symptom burden and their ability to deliver a higher level of primary palliative care. Further studies are needed to characterize the level of palliative care received among these patients. We recently found that oncologists with a more favorable attitude towards palliative care were not only more prepared to delivery primary palliative care to their patients, but also more likely to initiate early referral to specialist palliative care [44, 45]. Other strengths of this study include the relatively large sample size, the consecutive patient cohorts, the actual clinical setting, and the quasi-experimental design.

Based on our experience with this pilot program, the steering committee has made several recommendations to further optimize distress screening at our hospital. First, although social work triage was suggested by CoC as an intermediate step, the fact that our program only had one social worker limited our ability to triage more patients and for patients to be assessed in a timely fashion. We plan to modify the program flow such that a positive screen will trigger further assessment by a clinic nurse (instead of social worker), who will then discuss this with the oncologist to formulate a symptom distress management plan for the patient while he or she is still in clinic. Second, the threshold should be lowered such that any symptom with an intensity $\geq$7/10 will result in further assessment. Third, our team is building alerts into electronic health record to automatically notify clinicians if their patients screened positive. Further studies are needed to determine if these changes can streamline the process further and result in better outcomes.

Our study has several limitations. First, this is a single-center study with limited resources and a unique patient population. Thus, our experience may not be generalizable to other centers. Second, we did not collect data on quality of life or other clinical outcomes related to psychosocial service referral in this pilot project. Given that many patient-reported outcomes may fluctuate along the trajectory with cancer treatment and disease status, a randomized trial design may be needed to properly address these important questions. Third, because of staffing restrictions, we had to use a high threshold for referral, and our social worker was not able to contact the patients immediately. The CoC statement supports that each "cancer committee determines the cutoff score used to identify distressed patients" [7]; nevertheless, a lower threshold would likely catalyze a higher level of access to psychosocial care. Finally, we only collected data during three 4-week periods. Future studies should examine longer-term data to assess the sustainability of this program.

Conclusion

In summary, we were able to successfully implement a distress screening program in a resource-limited setting. This program was associated with increased symptom documentation and increased access to psychosocial care. We also identified several opportunities to streamline this process. Future studies are needed to determine the long-term impact of these programs on patient outcomes.

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Disclosures

Alyssa G. Rieber: Steris Corporation (E [spouse]). The other authors indicated no financial relationships.

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