



## Early Experience with Distress Screening in a Gynecologic Oncology Practice

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### Abstract

Starting in 2015 the American College of Surgeons Commission on Cancer required distress screening for patients at accredited cancer centers. Here we describe the impact on clinic operations of implementing a distress screening program in gynecologic oncology outpatients. Over 12 days, consecutive patients seen in a gynecologic oncology practice were asked to complete a distress screening questionnaire. We compared mean visit times during the study period to those of consecutive patients seen in the same practice from the preceding 12 days who were not screened. We also compared mean waiting room time, where the questionnaire was completed, and mean visit time by appointment type (new vs. return visit). Two hundred eighty-six patients were enrolled; 147 controls and 139 screened. The questionnaire was offered to 103 (74%) of 139 patients seen during the screening period. Nine patients (6%) declined screening, and 94 patients (68%) completed the questionnaire. Mean visit time was 69 min for the control group and 66 min during the screening period. No difference was found in mean waiting room time or in mean visit time after adjustment for visit type. These data suggest that efficient and effective integration of universal distress screening in a gynecologic oncology outpatient practice is feasible.

**Keywords:** Cancer; Distress; Gynecologic Oncology; Psychosocial; Screening

### Introduction

Psychosocial distress affects 30% to 43% of oncology patients in the ambulatory setting [1]. Dolbeault et al. [2] found that female gender was one of the risk factors associated with greater distress, speaking to the importance of psychosocial assessment and support in gynecologic cancer patients. The National Comprehensive Cancer Network (NCCN) defines distress as follows: "Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, and emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis" [3]. In 2012, the American College of Surgeons Commission on Cancer (CoC) Accreditation Committee released Cancer Program Standards, 2012: Ensuring Patient-Centered Care. The psychosocial distress screening standard (chapter 3, standard 3.2) specified that accredited programs must develop and implement a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care [4]. While the specific modality by which screening takes place was left to the discretion of individual institutions, the timing, frequency, assessment, referral, and documentation mandates are clearly delineated. Specifically, screening must be performed at least once for each cancer patient at the time of a pivotal medical visit. An oncologist, nurse, social worker, and/or psychologist is required to evaluate and address social and behavioral problems that interfere with the patient's ability to participate fully in their health care, including managing their illness and its consequences. As such, referral for appropriate psychosocial care and documentation in the medical record are also required. One of the aims of these criteria is to avoid screening questionnaires that are administered by mail or electronically in the absence of a face-to-face visit with the patient. Specifically, the CoC stated that all standards in Chapter 3 were to be implemented at accredited institutions by January 1, 2015. Mitchell et al. [5] evaluated the feasibility of distress screening implementation in the clinical setting and found that the majority of barriers to screening were issues related to the clinic staff and systems. Staff quoted lack of time and training,

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as well as a sentiment that screening was burdensome to the providers and clinic flow. Similarly, a lack of resources or support services for referral once psychosocial distress was identified was described as a source of frustration. This points to the importance of engaging key stakeholders in order for distress screening to be effectively integrated into the clinical care setting. Integration of distress screening is more likely to be successful if the clinic staff is engaged, if physicians view the screening process and results as valuable, and if an appropriate referral network for identified issues is in place. In this paper, we aim to describe the development of our distress screening program, as well as the impact of a screening pilot study in the gynecologic oncology outpatient setting on clinic operations.

## Materials and Methods

To determine the best approach for integration of a distress screening program into the ambulatory cancer care environment at our institution, we created a task force of representatives from nursing, psychiatry, social work, the Cancer Quality Committee, and the Patient Experience Advisory Council. Select task force members went to an intensive National Cancer Institute (NCI) supported training program at the City of Hope Comprehensive Cancer Center to learn how to create and implement a successful screening program. After reviewing existing validated screening tools in the literature, the task force created a brief screening tool comprised of 15 questions, covering topics ranging from fatigue, anxiety, depression, stress, and physical symptoms (Figure 1). We chose to call this a wellbeing questionnaire, as opposed to a distress screening tool, in order to avoid “pathologizing” the challenges that cancer patients face. Each question is scored on a scale of 0 to 3, and whether the patient wants more information or discussion on a topic is recorded. Members of the task force met with clinic staff before, during, and after the rollout of the distress screening pilot study to identify barriers, improve staff comfort levels with questionnaire administration and actionable results, and obtain feedback regarding workflow integration. The questionnaire was designed to be given to patients at each visit at the time of check-in, and would be completed by the patient in the waiting room. When the medical assistant called for the patient, the patient’s answers to the screening tool items were documented in the electronic medical record, and the completed screening tool document was given to the nurse. The nurse would then have a conversation with the patient about the scores, particularly addressing any category with a score greater than 0 or that the patient requested more information about. The nurse would then offer the patient a referral to members of the psychosocial service team and to community resources as needed. Furthermore, the nurse would discuss any medical problems identified on the screening tool with the physician. The distress screening program was piloted in the gynecologic oncology clinic. As this was a quality improvement activity with minimal risk, it was deemed exempt from approval by the Institutional Review Board. The objective of this pilot study was to determine the feasibility of universal distress screening and its impact on workflow in the clinic. The study group was comprised of consecutive patients seen from 7/7/14 to 7/18/14 who were asked to complete the wellbeing questionnaire. The control group was comprised of consecutive patients seen in the same practice from 6/23/14 to 7/4/14 who were not screened.

The primary outcome was mean appointment time, which was determined using electronic time stamps for check-in and check-out. Mean appointment times for the study and control groups were compared using the two-tailed, unpaired student’s t-test in

an intention-to-treat analysis. Secondary outcomes were mean time spent in the waiting room, where the questionnaire was completed, mean appointment time by visit type (new visit vs. return visit), and impact on clinic staff.

## Results

Two hundred eighty-six patients were enrolled in the study, with 147 unscreened controls (prior to implementation of screening) and 139 subjects in the screening cohort. The wellbeing questionnaire was offered to 103 (74%) of 139 patients in the screening cohort; 36 patients were not offered screening due to limited familiarity of clinic staff with the process early in the study. Nine patients (6%) declined to complete the questionnaire, and 94 patients (68%) completed it. No significant difference was noted in mean appointment time between the screened and unscreened groups, with a mean of 69 min for the control group and 66 min for the wellbeing screening group ( $p=0.43$ ). Of those patients in the wellbeing screening group who actually completed the questionnaire, the mean appointment time was 65 min. Similarly, no difference was found in mean waiting room times where the questionnaire was administered, with 24 min for the control group and 25 min for the wellbeing screening group ( $p=0.53$ ). After adjustment for visit type (new vs. return visit), screening was not found to be associated with an increase in mean appointment time. The duration of a new patient visit was 109 vs. 94 min ( $p=0.22$ ), while a return visit was 61 vs. 57 min ( $p=0.8$ ), for the control vs. screening group, respectively. These data suggest that wellbeing screening does not impair clinic efficiency. A survey of the clinic staff was performed before, during, and after implementation of the pilot study. Clinic staff exhibited a high level of anticipatory anxiety prior to the implementation of universal distress screening, which decreased over time. More patients were offered the questionnaire upon check-in after a “hard stop” reminder was incorporated into the electronic medical record, which improved the survey completion rate to 80%. The medical assistants and nurses reported increased communication with one another about the patients’ wellbeing. The oncologists noticed no negative impact to clinic operations or workflow.

## Discussion

The CoC standard for accredited cancer centers to develop and integrate a psychosocial distress screening program has highlighted the importance of identifying and addressing distress among our patients. However, the task of implementing such a program brings numerous questions that can be overwhelming for institutions embarking upon program development. These questions include how to conduct screening, what validated screening tool to use, how to integrate screening into the outpatient workflow, how to determine screening “cutoffs” indicative of distress, what to do with screening results, whether to use an automated referral system that is “triggered” by certain screening outcomes, how to ensure adequate resources and staff are available to address issues that are identified with screening, and more. In this paper we hope to demonstrate the successes and challenges we encountered with our own distress screening program integration. Positive foundational steps included participation in an NCI-supported training program for staff education prior to program development, engagement of key stakeholders in the process and outcomes, development of a brief yet comprehensive screening tool, and hands-on involvement of an oncology social worker with all steps of program initiation and implementation. Challenges included clinic staff apprehension and missed screening opportunities due to suboptimal workflow integration early in the program. Here we will

Please circle a number to indicate how much each of the following has distressed or bothered you during the past week, including today.					I'd like written information about this	I'd like to speak to someone about this
	None	Low	Mod	Hi		
1) Sleep / Energy / Fatigue	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
2) Anxiety / Nervousness / On edge	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
3) Depression / Sadness / Feeling down	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
4) Worry or Uncertainty about the Future	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
5) Physical Symptoms or Side Effects (e.g. pain, nausea, headaches)	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
6) Memory / Concentration / Thinking	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
7) Intimacy / Infertility	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
8) Prognosis / Course of Illness	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
9) Finances / Housing / Transportation	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
10) Concern about Friends / Family / Spouse	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
11) Being a Burden to Others	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
12) Worry / Ability to Cope with Stress / Emotional Issues	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
13) Spiritual / Religious Issues	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
14) Other: _____	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>
<b>15) Overall Distress Level</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<input type="checkbox"/>	<input type="checkbox"/>

**Figure 1:** Wellbeing Screening Tool developed by the University of California, San Diego. The form shown here is annotated for size. Patients receive a single-page, double-sided questionnaire with all instructions and questions in both English and Spanish, as well as an area to indicate who is completing the form and whether the answers are generated by the patient or by someone else.

expand on some of these topics in order to assist and guide other cancer centers with their own distress screening program development. The prevalence of psychosocial distress in cancer patients has been well-documented, and interventions aimed at reducing distress have been shown to improve quality of life [6]. Despite this, cancer patients as a whole underutilize psychosocial services [7], and this pattern is consistent when looking at women with gynecologic malignancies [8]. This underutilization is, in part, related to the poor rate of capture of distress among oncology patients. In fact, prior to the CoC mandate, concordance with the NCCN Distress Management Guidelines was only 20% among NCCN member institutions, and may have been lower at non-NCCN practices [9]. The majority of physicians working with cancer patients note a lack of confidence in dealing with distress, and report little training in the assessment and management of psychosocial issues [10]. Most physicians wait for the patient to initiate discussion of emotional and social issues, while 30% of patients defer to the physician to introduce the topic [11]. Thus, the CoC mandate has provided a unique opportunity to prioritize, standardize, and improve the assessment and management of psychosocial distress in cancer patients. The CoC has allowed for individualization of psychosocial distress screening implementation by each institution

in terms of the tools used for screening and the method in which screening is incorporated into the clinical setting. Wagner et al. [9] reviewed the use of a patient- vs. clinician-administered approach to screening. While clinician-administered screening allowed for real-time clarification of responses and feedback, this approach was time consuming and patients expressed some reluctance or hesitation in disclosure. In contrast, a patient-administered screening allowed for greater patient-perceived privacy, though it was imperative for clinicians to then be able to review and clarify any uncertainties or issues on the screening tool with the patient before the end of the encounter. The crucial finding, however, was that regardless of the approach for administration of the screening tool, a clear action plan for management of patients who reported distress needed to be in place. Mitchell et al. [12] similarly reported that the mere capture of a diagnosis of psychosocial distress did not improve outcomes, such as patient wellbeing and quality of life, without receipt of the appropriate aftercare. In addition, the specific assessment of unmet needs was an important adjunct to the evaluation of distress, and the availability of resources to address such needs was vital to the success of a screening program. Once a screening tool has been chosen and administered, the manner in which the results are interpreted and

acted upon can also be individualized by each institution. Meijer et al. [13] advise against the use of automated triage processes to identify and manage patients with distress. Although mechanized screening and numerical algorithms are often thought to be less likely to miss a diagnosis, many patients with low distress screening scores still seek and desire psychosocial support. Thus, while an automated referral system may fail to identify these patients, a coordinated care pathway that includes oncology social workers, nurses, psychologists, and psychiatrists when needed, is more likely to recognize and address the needs of these patients. Specifically, the incorporation of an oncology social worker into the cancer clinic workflow can increase the rate of referral for psychosocial services and significantly decrease the time to referral [14]. Interventions applied depend on what type of distress or unmet need is identified. While some unmet needs, particularly of financial or logistical nature, are addressed with social support services and patient care coordination, interventions for emotional distress and psychological functioning, including anxiety and depression, may include psychoeducation, cognitive-behavioral training, group supportive therapy, or individual supportive therapy [15]. While the CoC mandate only requires one distress screening per cancer patient, it is not always clear which clinical contact is considered to be the “pivotal visit” that the Standards Manual describes [16]. Thus, given the dynamic nature of psychosocial distress along the continuum of treatment, the incorporation of reassessment screens at various intervals in the patient’s clinical course may be prudent. Multiple barriers to the integration of a psychosocial distress screening program have been identified. Chiang et al. [17] identified the primary four barriers to screening as insufficient time for interaction with patients, lack of social service resources, lack of a private space in which to hold sensitive discussions with patients, and patient discomfort with disclosure. Staff anxiety about the impact of integrating distress screening on clinic workflow and provider burden is also a common barrier, as was noted during this pilot study of distress screening at our institution. As this can lead to hesitation to accept, or frank opposition to, new standards in the cancer center, care should be taken early in the program design to ensure buy-in from key stakeholders, including administration and patient care staff [16]. Clinic staff should be engaged in the creation of the workflow so that they feel included in the planning and invested in the results. Physicians should be reminded of the value that the identification and treatment of psychosocial distress adds to a patient’s ability to tolerate and complete cancer treatment, as well as its impact on quality of life. Finally, a referral network encompassing the array of available resources should be in place so as not overwhelm any one entity or group with new requests, and a gap analysis should be performed at regular intervals to identify areas in which resources are inadequate.

The benefits of psychosocial distress screening and management have been well-documented in the literature. Early on, improved communication between patients and clinicians is noted, which often assists in the recognition of an unmet need or care gap [5]. More recently, multiple studies have noted a cost benefit to the screening and detection of distress in cancer patients. In a study of breast cancer patients, Simpson et al. [18] found that women who were randomly assigned to receive six weekly structured group therapy sessions after the completion of their cancer treatment, as opposed to no intervention, showed improved adjustment and quality of life compared to the untreated group, and this effect was still evident two years after the intervention. As the study was conducted in Canada where a universal one-payer health system is in place, a calculation

of the cost offset, defined as the reduction in health care costs attributable to effective intervention, could be readily performed. The average amount billed to the health care system was 23.5% less for the treatment group during the two years following the intervention as compared to the control group. The investigators note that with this cost offset the intervention was entirely paid for in addition to further cost savings to the health system. It is also notable that the women in this study were not experiencing significantly elevated levels of distress prior to their enrollment. The positive outcomes seen with psychosocial intervention in cancer patients without documented distress speaks to the potential benefit of integrating some elements of psychosocial care into the treatment of all cancer patients, including those who do not meet criteria for distress upon screening.

## Study Limitations

There are several limitations to the current study. The study was conducted in a stepped wedge pre-post format, with a cohort of non-screened patients followed by a cohort of screened patients. While the use of consecutive patients in a given date range provides cross-sectional data that represents a typical population of gynecologic oncology outpatients at our institution, a randomized controlled trial would minimize any unforeseen variability (i.e. changes in staffing, for example) that might exist in the two separate time intervals. Furthermore, due to the nature of the pilot study, a limited timeframe was used for evaluation of each cohort. Use of a longer time period would provide a more representative fraction of patients. While a survey of staff members was conducted to determine what successes and obstacles were encountered during the pilot study, this was done by gathering written comments from the involved staff. This feedback in prose, while useful for quality improvement, was not a quantifiable measure that could be analyzed and reported in this manuscript. In addition, as the pilot study aim was to determine the impact on clinic workflow and efficiency, we did not capture many other important factors, such as the prevalence of distress in our patients, patient characteristics, the number of patients who were referred for support services, and the time interval from identification of distress to intervention. It should be noted that some related findings, such as patient characteristics and the time from initial presentation to social work referral, were reported in a previous study by our group and thus were not aim of this study [14]. However, capturing this additional data would have offered further insight into our pilot study patient cohort in comparison to the previously studied patient group. Finally, as this was a single institution study, the generalizability of our findings is limited. Capture of the above-described factors in real-time along with a multi-institutional approach is recommended for future research.

## Clinical Implications

This pilot study addresses an important clinical practice need of cancer institutions and offers insight that impacts the delivery of care. Our results provide pragmatic considerations for CoC-accredited cancer centers who are integrating a distress screening program into their outpatient workflow. Strengths of our study include the attendance of several cancer care team members from different areas of specialty to an NCI-supported training program focused on the creation and implementation of a distress screening program. From this task force we designated “wellbeing champions,” who were able to meet with staff in the outpatient clinic before, during, and after the pilot study to ensure smooth integration of the program and identify areas for improvement. The knowledge gleaned from this

training also allowed us to better define our institutional goals from a distress screening program, and thereby delineate what specific information we hoped to glean from a screening tool. We performed a comprehensive review of existing, validated distress screening tools and developed a succinct but inclusive wellbeing questionnaire to suit our needs. Our screening tool reviews a broad array of psychosocial and emotional aspects of a patient's wellbeing and has been vetted via a reliability study. This tool provides a level of detail that many existing validated tools, such as the distress thermometer or other two-step screening modalities, are lacking, which allows the clinician to better tailor recommendations for intervention directly from the initial encounter [19]. As the NCI-supported training program we attended is competitively selected for, not every CoC-accredited cancer center has the ability to participate in such a program. Thus, we hope the results from our pilot study, including the successes and challenges we faced, will serve as a means to guide other centers as they integrate a high-quality, efficient, and effective distress screening program into their clinical practice.

## Conclusion

In 2007 the Institute of Medicine released a report entitled "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs," reflecting the importance of patient-centered care in oncology. The emphasis on screening and management of psychosocial distress in cancer patients has resulted in new standards for CoC-accredited cancer centers, which many sites are still working to comply with. Here we demonstrate that effective and efficient integration of universal wellbeing screening in a gynecologic oncology outpatient practice is feasible. Buy-in from cancer center administration and staff is important for a cohesive approach. Pre-implementation education may diminish anticipatory anxiety among clinic staff, and real-time reminders in the electronic medical record may ensure higher rates of compliance with screening. The presence of an oncology social worker in the clinic at the time of the implementation may help to facilitate the process and accelerate success.

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