

Demonstrating Measurable Value: Distress Screening



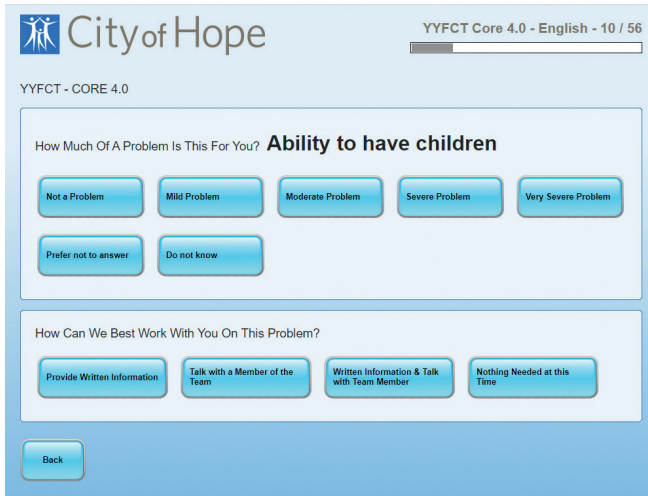
A digital tool connects patients to critical supportive care services

A CCC President Krista Nelson, MSW, LCSW, OSW-C, FAOSW, chose to highlight “Real-World Lessons from COVID-19: Driving Oncology Care Forward” as her 2021-2022 President’s Theme. The focus is on three critical lessons learned that alert the oncology community of urgent and emerging needs fueled by the ongoing effects of the pandemic. One of these learnings is that “the escalating need for high reach, high impact psychosocial and supportive care services require innovative care delivery models that demonstrate measurable value to the oncology ecosystem.”

Since 2015 the Commission on Cancer (CoC) has required a systematic protocol for psychosocial distress screening and referral as a condition for cancer program accreditation. In 2020 the CoC released new accreditation standards with the publication of *Optimal Resources for Cancer Care: 2020 Standards*, which were updated in Feb. 2021. Standard 5.2 Psychosocial Distress Screening requires that cancer programs “implement a policy and procedure for psychosocial distress screening for cancer patients.”¹ The standard states that the screening process should identify “psychological, social, financial, and behavioral issues that may interfere with a patient’s treatment plan and adversely affect treatment outcomes.”¹ When patients are identified as having distress, the cancer program should have appropriate resources available either in-house or by referral. The standard calls for patients to be screened at least once during their first course of treatment, and the program’s cancer committee has leeway to determine the screening mode. Effectively integrating distress screening into practice continues to be a challenge for some cancer programs.



Karen Clark, MS, manager, Supportive Care Programs.
Photo courtesy of City of Hope.



The City of Hope digital screening tool, *SupportScreen*.

In 2007 City of Hope, a comprehensive cancer center near Los Angeles, first implemented its digital touch-screen screening tool. *Oncology Issues* recently talked with Karen Clark, MS, manager of Supportive Care Programs, City of Hope, about the process, how the tool is currently integrated into the electronic health record (EHR), and next steps. Led by City of Hope's Matthew J. Loscalzo, LCSW, FAPOS, executive director, People & Enterprise Transformation; emeritus professor, Supportive Care Medicine; professor, Population Sciences; Clark and a multidisciplinary team pioneered the development of this digital distress screening tool for patients with cancer that encompasses biopsychosocial domains.

OI. How did you become interested in Supportive Care in oncology?

Clark. In 2004, I was introduced to the Science of Caring when I met Matthew Loscalzo. We were working at the Moores Cancer Center at UCSD [University of California San Diego] at the time. I was inspired by the thought that I could make a difference in patients' and families' lives when they are going through one of the most difficult times. If meaning and growth can be gained through difficult times, I truly believe this is the best outcome. Life can be very hard, so it is important to have as many tools as possible to be able to cope in the best way possible.

My role at City of Hope is manager of Supportive Care Programs. I also lead research operations for this department. I work with a team to build supportive care medicine programs and teach others across the country how to build supportive care programs to enhance the quality of life of patients and their families.

OI. Can you briefly describe the development of the City of Hope digital screening tool, *SupportScreen*?

Clark. With a multidisciplinary team, patient and family feedback, and IT support, Matthew and I led the development of *SupportScreen*,² an automated touch-screen system that identifies, summarizes, and triages patient biopsychosocial problems in real time. It can facilitate patient, physician, and specialist communication through an electronic interface built to be user-friendly and compatible with most standard patient software systems. *SupportScreen* also provides customized reports for clinical, educational, and research purposes. The content of *SupportScreen* is, "You, Your Family, and City of Hope are a Team," which has also been validated at City of Hope.³

OI. How long has the electronic version been in use and how have cultural considerations been taken into account?

Clark. *SupportScreen* has been in use at City of Hope since 2007. Today, screening is only offered electronically and is available in English, Spanish, and traditional Chinese (i.e., one of the two forms of written Chinese). In the translation process, Sharon Baik, PhD, assistant professor in the Department of Supportive Care Medicine, one of our new research faculty members, is working on developing culturally tailored technology to improve quality of life in Latinx gynecology patients.

OI. Can you walk us through how *SupportScreen* works?

Clark. The digital screening tool is integrated with our Epic system, which creates an alert; so the biopsychosocial screening is built into the standard of care at City of Hope. Patients are screened at their first or second visit. When patients check in to the clinic, they are handed an iPad. They have a specific 15-minute appointment designated to psychosocial screening. In this way, we ensure that the screening process does not disrupt the clinic. We need to make sure that clinical flow is efficient and running smoothly and that patients get in to see their doctor on time. We have the distress screening as a protected time so that patients can focus on completing the *SupportScreen*. This allows us to proactively identify problem areas or patient distress upfront and then automatically connect patients to resources. *SupportScreen* is pre-programmed so that all the triage happens in real time based on the patient's response. The system can generate five possible outputs: 1) summary report for the physician (printed and/or electronic); 2) tailored educational information in print for patients; 3) personalized resources for patients; 4) criteria-driven referrals to professionals and community-based resources; and 5) individual patient responses recorded into a database for analysis.

So whether it is a referral to one of their primary healthcare team members or the patient wants written information—or maybe they want both—the system will create personalized emails

that go out to some of our other supportive care services, such as nutrition, rehabilitation, and financial counselors, and will link the patient to those providers, depending on the specific expressed need.

One output is an email that is generated and sent to the primary healthcare team—physician, nurse, and social worker. We also have a copy of that summary report going into the EHR. Anyone who is caring for that patient can go into the EHR and see what is being done in terms of supportive care follow-up and what issues were flagged. So, for example, the physician can see what social work is working on for the patient. Everyone on the team has a nice picture of the coordinated care.

OI. How often are patients screened using the touch-screen tool?

Clark. Currently patients are screened once at the first or second visit to their medical oncologist or surgeon. However, we would like to rescreen patients at 30 days or greater and at other critical treatment points. At present, however, *SupportScreen* does not have the capability to automatically flag patients for rescreening at these time points.

OI. Is *SupportScreen* integrated with the patient portal?

Clark. Not yet. The patient portal has not yet had huge adoption overall, so we did not want to be dependent on it for this screening. But there is an option for patients to go into the portal and complete the screen before their appointment.

OI. Can you explain what happens, for example, when patients indicate that fertility is a problem?

Clark. This [concern] is built into the screening process. An item on *SupportScreen* asks patients to indicate how much the ability to have children is a problem for them (i.e., on a scale from *not at all* to *very severe*). Then, patients are asked, “How can we best work with you on this problem?” They have the following response choices: nothing at this time, written information, talk with a member of the team, and both. If patients rate the problem as moderate to very severe or if they indicate that they want to talk with a member of the team, it triggers a referral to their physician. In addition, print materials are offered if patients need more information.

OI. What other types of screening are employed to elicit concerns about sexual functioning and potential for infertility?

Clark. Through the Women’s Center, patients with breast cancer are screened during survivorship to identify concerns related to survivorship post-treatment. In addition, in the adolescent and young adult population there is a bigger concern that is identified through our screening.⁴

Ability to Have Children: Fertility Issues

Radiation therapy and chemotherapy treatments may cause temporary or permanent infertility. These side effects are related to a number of factors including the patient's sex, age at time of treatment, the specific type and dose of radiation therapy and/or chemotherapy, the use of single therapy or many therapies, and length of time since treatment.

When cancer or its treatment may cause infertility or sexual dysfunction, every effort should be made to inform and educate the patient about this possibility. When the patient is a child, this can be difficult. The child may be too young to understand issues involving infertility or sexuality, or parents may choose to shield the child from these issues.

Chemotherapy

For patients receiving chemotherapy, age is an important factor and recovery improves the longer the patient is off chemotherapy. Chemotherapy drugs that have been shown to affect fertility include: busulfan, melphalan, cyclophosphamide, cisplatin, chlorambucil, mustard, carmustine, lomustine, vinblastine, cytarabine, and procarbazine. In women older than 40 years, adjuvant endocrine therapy increases the risk that chemotherapy will cause permanent loss of menstrual periods.

Radiation

For men and women receiving radiation therapy to the abdomen or pelvis, the amount of radiation directly to the testes or ovaries is an important factor. In women older than 40 years, infertility may occur at lower doses of radiation. Fertility may be preserved by the use of modern radiation therapy techniques and the use of lead shields to protect the testes. Women may undergo surgery to protect the ovaries by moving them out of the field of radiation.

Fertility Alternatives

Patients who are concerned about the effects of cancer treatment on their ability to have children should discuss this with their doctor before treatment. The doctor can recommend a counselor or fertility specialist who can discuss available options and help patients and their ovarians through the decision-making process. Options may include freezing sperm, eggs, or ovarian tissue before cancer treatment.

Resources on Fertility Preservation for Cancer Survivors

Oncofertility Consortium (<http://oncofertility.northwestern.edu>)
NIH-supported interdisciplinary research consortium exploring relationships between health, disease, survivorship, and fertility preservation in young cancer patients

MyOncofertility.org
Patient education resource provided by the Oncofertility Consortium
Fertile Hope (www.fertilehope.org)

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Nonprofit organization affiliated with the Lance Armstrong Foundation that provides information and support to cancer patients and survivors at risk for infertility

American Society of Clinical Oncology (www.asco.org)
Recommendations on fertility preservation in people treated for cancer

Livestrong.org (www.livestrong.org)
Founded in 1997 by Lance Armstrong, Livestrong offers information for cancer patients on a variety of topics including fertility information.

Local Resources for Sperm Banking, Egg and Embryo Preservation

The following resources are listed as a convenience for our patients and do not constitute an endorsement by City of Hope.

- Fertile Future Sperm, egg, embryo storage
www.fertile-future.com/
- Huntington Reproductive Center Medical Group Fertility treatment, egg freezing
www.havingbabies.com
- Live: On Sperm banking kit by mail for cancer patients
www.liveonkit.com

Financial Considerations

Although some insurance companies will often pay for infertility treatments, procedures such as sperm banking, egg freezing and embryo freezing are usually not covered. Since insurance coverage varies widely we encourage you to discuss these options with your insurance company.

Financial assistance program are available through organizations such as Fertile Hope's Sharing Hope program. Find out more at www.fertilehope.org.

Resources Available at City of Hope

It is important that you talk with your doctor about your concerns and your options. You may find helpful information, education and support in the Sheri and Les Biller Patient and Family Resource Center located near the entrance to the Main Medical building or call 626-218-CARE (2273).

References

- This information was summarized or adapted from the following sources:
- <https://www.cancer.gov/about-cancer/treatment/research/fertility-preservation>
 - <https://www.cancer.gov/about-cancer/treatment/side-effects/fertility-women> June 2017.

Patient, Family & Community Education
14.1/34.5 May 2011
Ability to have children- Fertility 2011-0625.doc
Updated 2018
patienteducation@coho.org

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OI. Who handles these discussions?

Clark. The patient's medical oncologist.

OI. Are patients triaged to resources available at the main City of Hope campus, in the community, or both?

Clark. Both. We have a community resources coordinator who works with patients and families to connect them with community resources.

OI. Because the patient's experience and course of treatment often evolve over time, with new treatments raising new concerns—how is that addressed?

Clark. Screening links the patients with resources at their initial visit; however, they [patients] should be rescreened at 30 days or greater and at pivotal points in their treatment. We also have social workers who are available to patients over the course of their treatment to address their needs over time.

OI. For example, a patient on active treatment is seeing an advanced practitioner and suddenly mentions some areas of psychosocial distress. How is that handled?

Clark. It depends on the issue. If it is more psychological, patients would be referred back to social work or psychology. If it is more practical—for example, patients need help figuring out their financial options—then a financial counselor or social worker would be pulled in. There are a lot of different options depending on the root of the problem.

OI. From previous studies, low socio-economic status is associated with patients' levels of biopsychosocial distress.⁵ Onco-fertility treatments can be costly, especially for women. Is there discussion and support for concerns about affording this treatment?

Clark. Yes, please see the resource on page 21. We also have financial counselors and social workers to help link patients with additional financial resources.


OI. Is fertility an ongoing area of research for City of Hope?

Clark. Yes, through survivorship planning. Our newest faculty member, Dr. Sharon Baik, is developing culturally specific, tailored psychosocial interventions for Latinx gynecology patients, which will include fertility issues.

OI. What kind of feedback have you had on the digital screening tool?

Clark. One benefit to this screening process is that responses tend to be more honest. It brings these issues to mind just by asking: Is this a problem for you? How can we best help you with this? It may be that it is not a problem but the patient still would like information on the issue, and at least we are able to provide that upfront. We provide a lot of different ways for patients to let us know. For example, sometimes patients are screened early on and some problem is flagged. Now patients are in the system and a social worker or one of the other healthcare team members is following up with them. They [clinicians or other staff] can do a check-in and follow-up verbally, not via a formal assessment or screening, which is what we would ideally like. That is our goal. Currently, we are limited in that the [interface] does not allow for a systematic way to identify patients for re-screening at a specific time interval. And we do not have the manpower to manually track all those patients and flag them in the system.

OI. Any learnings and/or practical resources or strategies you can share with cancer programs and practices that are less well-resourced than City of Hope?

Clark. Use the resources you have. In other words, do not wait for the resources but leverage what you have. Create a resource inventory and screen for the problems you can do something about. Automation is very helpful to link patients to community resources and education to save staff resources.⁶ 

Amanda Patton, MA, is a freelance healthcare writer. She worked as a senior writer and editor for the Association of Community Cancer Centers for more than 15 years.

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2. Loscalzo M, Clark K, Dillehunt J, Rinehart R, et al. SupportScreen: a model for improving patient outcomes. *J Natl Compr Cancer Ntwk*. 2010;8(4):496-504.
3. Wong FL, Stiller T, Obenchain R, et al. Validation of a biopsychosocial distress screening tool, "You, Your Family and City of Hope Are a Team." *Psycho-Oncol*. 2019;28(12):2396-2405.
4. Dawson EW, Clark K, Obenchain R, Loscalzo MJ, et al. Biopsychosocial distress in young adult oncology patients: examining sex differences in sources of high distress and requests for assistance. *J Adolesc Young Adult Oncol*. 2018;7(3):367-373.
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