TRANSFORMING
Cancer Care

The Impact of the Supportive Oncology Collaborative 2014-2021

The Coleman Foundation

A consortium of healthcare professionals working together to improve supportive cancer care.
Funded by: The Coleman Foundation

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EXECUTIVE SUMMARY

The Coleman Foundation was founded in 1951 to improve the quality of life in the Chicago metropolitan area through funding programs that are practical, financially sustainable, and results-oriented. For decades, cancer care and supportive oncology had been part of the Foundation's grantmaking, and to this day, cancer care continues to be a strategic interest of the Foundation. The next generation of Coleman's investments in cancer includes strategies in both prevention and supportive oncology. These investments are aligned with Coleman's current strategic plan, which has an overarching goal of increasing equitable health outcomes so there is a higher quality of life among the underserved and under-resourced.

The purpose of this report is to share how The Coleman Foundation helped build the Supportive Oncology Collaborative through strategic partnerships, a clear plan of action, and engaging multiple working groups. The report showcases how the Supportive Oncology Collaborative used evidence-based results to strengthen the deliverables it created in the form of toolkits and resources to share with a diverse group of stakeholders. These stakeholders can leverage this report as a case study and detailed road map for their programming and fundraising.

The Need for Supportive Oncology in Cancer Care

With new cancer therapies and treatments, better survival rates, and an aging population, there is a vital need for supportive care services. Cancer care often focuses on chemotherapy and radiation, surgeries, and end-of-life care. Little, if any, support is provided when it comes to supportive care services unless it is already part of a more holistic plan.

> *This is why the Supportive Oncology Collaborative's work has been an essential part of a cancer patient's journey.*

The National Cancer Institute defines supportive care for cancer as "care given to improve the quality of life of people who have an illness or disease by preventing or treating, as early as possible, the symptoms of the disease and the side effects caused by treatment. Supportive care includes physical, psychological, social, and spiritual support for patients and their families. There

SUPPORTING PATIENTS DURING THEIR CANCER JOURNEY

are many types of supportive care. Examples include pain management, nutritional support, counseling, exercise, music therapy, meditation, and palliative care. Supportive care may be given with other treatments from the time of diagnosis until the end of life."

When the Institute of Medicine* (IOM) released "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis" in 2013, the report set in motion recommendations that include supportive oncology. It recognized the role supportive oncology could play in a patient's cancer journey, which includes everything from accurate diagnosis and management to psychosocial support and better health outcomes.

Additionally, The Coleman Foundation already had a long-standing commitment to funding cancer care services and contributed nearly $30 million to support treatment and patient services for over 32 years. Therefore, when the IOM report was released, the Foundation recognized it was the right time to spearhead a major initiative around supportive oncology. The Supportive Oncology Collaborative built upon Coleman's deep relationships with cancer programs in communities and hospitals.

The Coleman Foundation's Impact on Cancer Care: An Exemplary Case Study

For decades, The Coleman Foundation funded cancer programs to improve the quality of life for cancer patients and survivors in the Chicagoland area. Through its strategic approach, the Foundation has exemplified how grantmaking can make a true difference in the lives of patients, their families, and our communities.

That unwavering support of healthcare providers and patients has guided the Foundation's work. On the heels of the IOM's report release, The Coleman Foundation launched and fully funded the Supportive Oncology Collaborative (SOC) in 2014, an ambitious initiative that builds upon its experience to improve cancer care. SOC participants included over 170 doctors, nurses, social workers, and advanced care professionals across many Chicago-area healthcare institutions.

By the end of 2021, The Coleman Foundation's impact had been felt by tens of thousands of patients throughout the Chicagoland area. This was achieved through numerous resources developed and designed to address disparities in health care and supportive care concerns for patients, regardless of where they received services, to ultimately improve health outcomes.

Building Partnerships for Supportive Oncology: Lessons Learned and Best Practices

The Supportive Oncology Collaborative developed work groups to tackle gaps in cancer care that practitioners identified. The participants worked together across institutions to find better ways to provide patient-centered care and equity in access to supportive care. The SOC included safety net, community, public, veterans, and academic hospitals and medical centers. The tools created were used to screen patients for supportive care needs for psychological, social, emotional, and non-medical factors that influence health outcomes, known as social determinants of health. In the next column are some of the tools and resources it created together.

Tools and Resources Developed by the Supportive Oncology Collaborative

8 patient distress and supportive needs screening tools

51 physician resource documents

26 professional training videos for continued medical education credit

60 abstracts and presentations for publications

73 patient self-management handouts, with links to verified resources

Comprehensive Tool Kit designed for cancer centers to provide ongoing quality improvements in Supportive Oncology Care

Cancer Take Charge Card customized for patient and treatment site

From Theory to Practice: Implementing Supportive Oncology Care in Hospitals and Cancer Centers

The SOC provided evidence of its impact through 60 publications and conference sessions at prestigious medical conferences. This evidence, plus media stories and active communication from participating institutions, helped to leverage the SOC's influence to show the professional community, payers, and the public how supportive services can lead to improvements in cancer care.

> *The SOC initiative exemplifies how grantmaking can make real and lasting changes beyond the initial front-line clinicians or patients undergoing cancer treatment.*

Building Sustainable Supportive Oncology Programs

From 2014 to 2021, The Coleman Foundation's funding to the SOC built a movement by supporting essential initiatives throughout the process and helping to build crucial partnerships across institutions and community providers that will last for decades. It invested nearly $8 million towards adult, pediatric, adolescent, and young adult (AYA) supportive oncology programs at 17 institutions. The tools and practice models created through the SOC spread throughout cancer clinics and programs at participating institutions. More than 100 institutions nationwide registered and gained access to the online SOC tools and resources.

The SOC's success can be attributed to its inclusive, interdisciplinary, and non-hierarchical approach, which enabled its participants to work together to identify and solve challenges. The SOC developed systems and tools that improved providers' skills and abilities to address cancer patients' quality of life and made those resources available to the larger healthcare community. The SOC's impact has been significant — the number of cancer patients screened for supportive care concerns at participating hospitals and medical centers increased from 17% at the beginning of the initiative to over 85% by the end of 2021. The SOC created various tools and resources and improved reimbursement for comprehensive supportive oncology. The Collaborative's outcomes have been robust, including partnerships between multiple service providers, enhanced supportive oncology processes across several medical facilities, and workforce development to improve understanding of supportive oncology guidelines and best practices.

Moving On and Leveraging Supportive Oncology to Improve Health Outcomes

In 2022, the Foundation transferred the resources created by the Supportive Oncology Collaborative to Equal Hope. As a non-profit that advocates for equity in access to high-quality cancer prevention and care, Equal Hope will be able to make the SOC's resources broadly accessible to cancer care providers, patients, and caregivers. These resources are housed on Equal Hope's website, providing information regarding cancer education, screening tools, treatments, self-care, and community resources. Equal Hope is currently working to expand public utilization by translating key resources into Spanish, and creating literacy level appropriate tools to compliment the site. Additionally, Equal Hope disseminates these resources widely, through their on-the-ground outreach and programming, social media platforms (e.g., Facebook and Twitter), and their weekly WVON 1690 AM radio show *Equal Health for All*, airing every Saturday morning.

The Coleman Foundation continues its commitment to programs and services that promote supportive oncology. Starting in 2022, the next generation of Coleman's investments in supportive oncology places a particular emphasis on reducing cancer disparities among communities of high need in the Chicago metropolitan area. In the continuation of its support, Coleman has invested in both new and former grantee partners who address social determinants of health, improve access to care, and provide culturally tailored education and treatment.

FROM 2022 TO THE PRESENT DAY,
The Coleman Foundation made nearly 40 grants in supportive oncology totaling over $1.5 million.

This report has been designed to showcase the immense power and far-reaching impact the Supportive Oncology Collaborative has had and continues to have on cancer care throughout Chicagoland and beyond. The lessons learned and recommendations developed, including the SOC toolkit, supportive care units, and growth in staff positions, have a ripple effect across the field. The Coleman Foundation hopes that this report can serve as a catalyst for other philanthropic organizations to build upon this work and show provider sites across the nation how they, too, can build something as impactful as the Supportive Oncology Collaborative within their own institutions.

**Institute of Medicine became the National Academy of Medicine in July 2015. Since SOC was formed before the organization changed its name, it is referred to throughout this report as the Institute of Medicine or IOM.*

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INTRODUCTION

For decades, The Coleman Foundation has funded cancer programs to improve the quality of life for cancer patients and survivors in the Chicagoland area.

The Foundation has a long-standing commitment to funding cancer care services and contributed nearly $30 million to support cancer treatment and patient services over the past 32 years. The Foundation has also had a long-held belief that supportive oncology services improve patients' quality of life, improve quality of care, and frequently lead to reduced care costs and patients living longer.

When national cancer organizations, such as the Institute of Medicine (IOM) and the Commission on Cancer (COC), recognized the outsized role supportive oncology could play in improving cancer care and recommended supportive service delivery, The Coleman Foundation knew it was the right time to spearhead a significant initiative.

In 2013, the Institute of Medicine released a report titled “Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis,” and it recognized the role of supportive oncology in a patient's cancer journey, which includes everything from accurate diagnosis and management to psychosocial support and better health outcomes. It also set in motion recommendations that include supportive oncology services.

While most Chicago cancer care providers had implemented or started the implementation of some aspects of supportive oncology, none had achieved the level of quality and service delivery demanded by the IOM report. Providers were wrestling with implementing effective changes in supportive oncology that addressed recommendations and requirements while adapting to local/regional healthcare guidelines, resources, and patient needs.

These catalysts led to The Coleman Foundation building the Supportive Oncology Collaborative (SOC) in 2014, an initiative that builds upon its experience to improve cancer care. The Collaborative was a network of over 170 doctors, nurses, social workers, and advanced care professionals across Chicago-area healthcare institutions. The overarching goal of the SOC was to improve access to supportive cancer care for all Chicagoland area patients, regardless of race, gender, ability to pay, zip code, or age.

IMPROVING QUALITY OF LIFE FOR THOSE LIVING WITH CANCER

FROM 2014 THROUGH 2021, *the SOC published resources for providers and patients and made them freely available online. These resources are available today on the Equal Hope website at equalhope.org/focus-areas/supportive-oncology.*

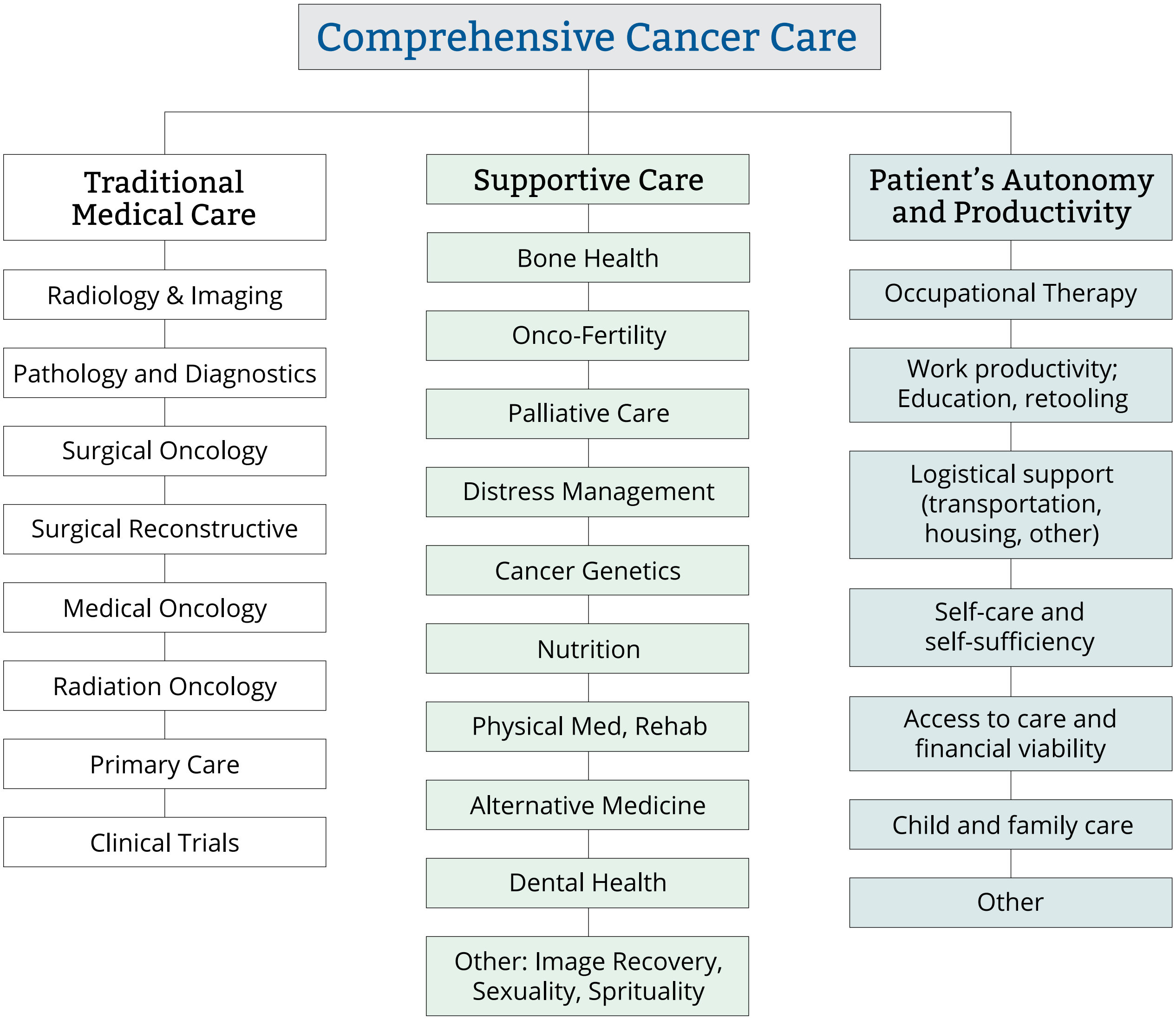
The Roadmap of the Supportive Oncology Collaborative

The Supportive Oncology Collaborative, realizing each cancer center defined supportive oncology differently, began the process in three steps. The three-step process included:

- Structured discussions with over 100 stakeholders involved in cancer care
- Workshop with over 70 grantees
- Survey stakeholders to provide feedback and prioritize program strategies.

The graphic below was used to help classify supportive oncology based on how each center worked. The SOC addressed supportive care and concerns that impact the patient's autonomy and productivity.

Figure 1: Comprehensive Cancer Care



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The Coleman Foundation started the process by organizing structured discussions with over 100 stakeholders involved in cancer care. This was essential to understand better how each stakeholder saw their role in supportive oncology.

Workshops with more than 70 participants from various Coleman grantee institutions allowed the SOC to explore the landscape of supportive oncology services throughout the Chicagoland area. This resulted in recommended strategies to improve the continuum of care patients receive. The Collaborative also surveyed stakeholders to provide feedback and prioritize program strategies.

The Coleman Foundation hired the Center for Business Models in Healthcare (CBM-HC) to structure, facilitate and guide the Collaborative's work in 2014.

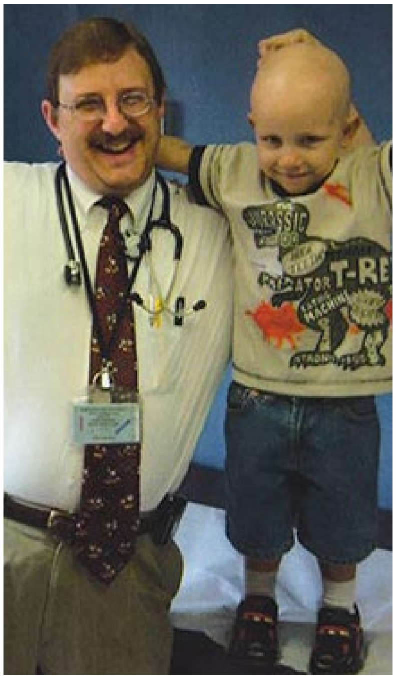
Additionally, in 2016, Amdur Spitz & Associates, Inc. was hired to help build a movement for supportive oncology, communicate the impacts of the Collaborative's work, create a platform to share resources and stories, and to spread supportive care services to other cancer clinics.

Achievements of the Supportive Oncology Collaborative

The impact of the Supportive Oncology Collaborative must be considered.

Thanks to the SOC:

- 85% of patients at participating cancer centers were screened for supportive care concerns, a fivefold increase from a baseline of 17%. In the participating SOC clinics, all patients were referred to indicated services.
- Since 2015, over 60,000 Coleman Grantee cancer patients in Chicago have been screened using a tool to identify care concerns that address a breadth of the social determinants of health. All but two sites used the SOC screening too.
- Participating Coleman grantees had nine social workers when the SOC started. During the program, that number increased to 25 social workers across the same sites based on the proven patient needs for social work services during the course of the SOC.
- Participating Coleman grantees increased outpatient palliative care staff.



While The Coleman Foundation launched and funded the collaboration, the sheer commitment, determination, and tireless efforts of what grew to be a team of 170 healthcare providers made the SOC a success. These providers represented 44 cancer care programs in organizations including: academic, community, public, Veterans Administration, and safety-net hospitals; community supportive oncology centers; palliative and hospice organizations; and patient advocacy groups.

The Coleman Foundation is proud to have stood behind the SOC and remains committed to ensuring cancer patients and their families receive the highest quality of care and service. As a result of many healthcare providers coming together to support cancer patients, as well as their caregivers and communities, a significant number of cancer patients in the Chicagoland area are now screened for supportive care needs and provided with access to services and resources.

Although the SOC has not changed the cancer trajectory for all patients, The Coleman Foundation's focus and support of cancer programming has made living with cancer easier, less stressful, and better for thousands of patients and their families.

This impact report highlights the culmination of Coleman's funding for cancer support, supportive oncology, encouraging collaboration among service providers, and recommending patient-centered care that provides individuals with the best possible outcome and quality of life. It is also hoped that other institutions impacted by this work might consider adding or expanding supportive care within their institutions.

As such, the report provides an overview of the Supportive Oncology Collaborative and highlights its objectives, strategies, participants, implementation models, resources, outcomes, and continued focus on delivering supportive oncology care to help improve the quality of life of cancer patients.

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WHAT IS SUPPORTIVE ONCOLOGY AND WHY IT MATTERS

What is Supportive Oncology?

Part of the definition of supportive oncology can be found in the name. Supportive oncology is meant to support the whole person. Supportive care means providing physical, emotional, practical and spiritual needs to patients and their families. This includes one's psychosocial and psychological needs, according to the National Cancer Institute.

The goal of the Supportive Oncology Collaborative was to improve quality of life during all phases of cancer treatment, regardless of prognosis or stage of the disease. Not just for the patient, but for their entire support team, whether a spouse, child, sibling, caregiver, colleague, or friend.

Why was The Supportive Oncology Collaborative needed?

Until now, healthcare providers knew their patients needed additional support to meet their needs but didn't always know where to send them or their loved ones to get those services or support. For example:

- A single mother diagnosed with stage 3 breast cancer doesn't know how to manage transportation to and from clinics and child care.
- A patient struggles to find the will to continue his treatments. He is suffering from depression, constant nausea, and overwhelming fatigue.
- A couple is overwhelmed caring for a child with a malignant brain tumor and concerned about the mental health of her two siblings.

A cancer diagnosis doesn't affect one person. There is a ripple effect in one's close circle of family, friends, and community. The National Comprehensive Cancer Network (NCCN), Institute of Medicine (IOM), and Commission on Cancer (COC) all recognized the need to include supportive services in comprehensive cancer care, but there was little clear direction on the guidelines. The Supportive Oncology Collaborative worked to put more definition and practical solutions behind the guidelines and recommendations.

PROVIDING COMPASSIONATE CARE FOR THE PERSON BEYOND THEIR DIAGNOSIS

Together the Supportive Oncology Collaborative worked to:

- create systemic practice models to screen for supportive care needs and make quality referrals for services in clinical practices,
- design tools and resources to be used by all members of the care teams in every type of care setting
- provide training and education for all members of the care team, and
- create an evidence base to persuade payers and other cancer centers to provide supportive cancer care to their patients.

What are Supportive Oncology Services?

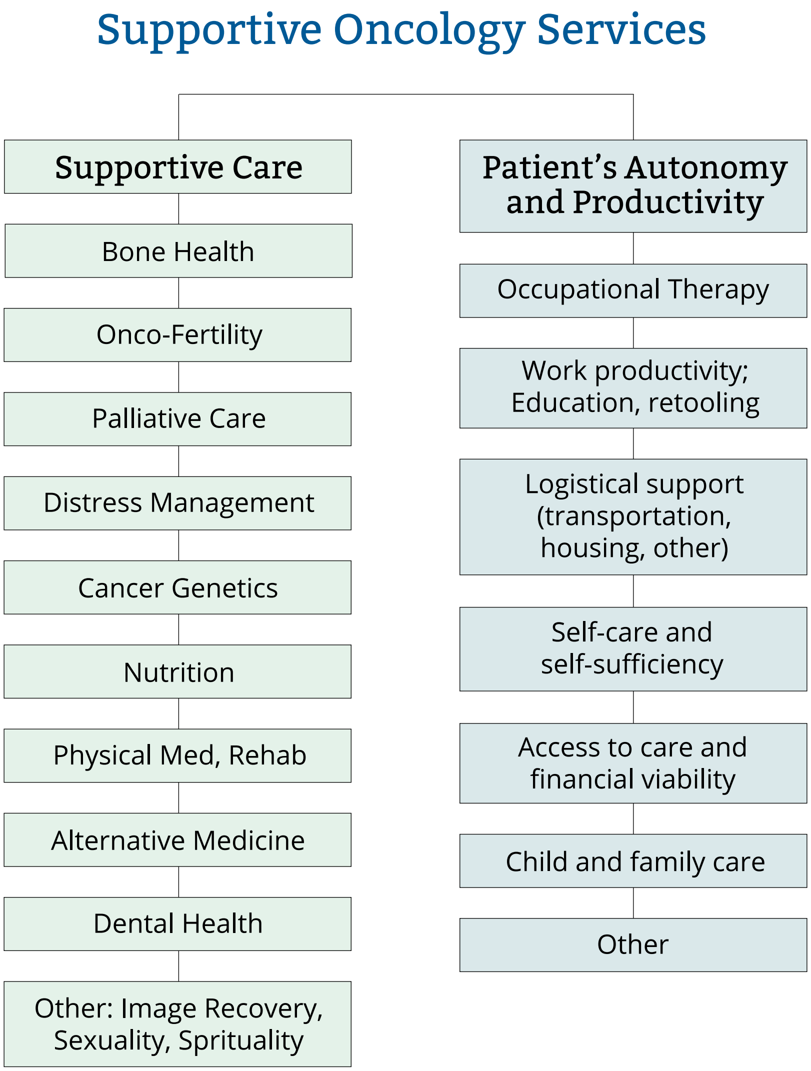
Supportive oncology includes services that can assist individuals from diagnosis to treatment, post-treatment through survivorship. It focuses on patient-centered care and treats the whole cancer experience rather than only treating a patient's medical condition.

An interdisciplinary team provides supportive services. Doctors, nurses, social workers, physician assistants, clergy, as well as community services providers all work together to support a patient and their family.

Unlike hospice care, which works to comfort those nearing the end of life, supportive oncology services are delivered any time and at any stage of cancer to relieve stress, pain, and other symptoms.

Supportive Oncology services provide all the supportive care services listed in this diagram, plus services needed to help the patient retain or regain autonomy and productivity.

Figure 2: Comprehensive Cancer Care



When Should Supportive Oncology Care Begin?

According to the IOM report, "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis," supportive care for cancer patients and their families should start at diagnosis and continue throughout the cancer journey. It can help patients understand their diagnoses and their treatment options and plan. Supportive care should be provided alongside medical treatments to help patients manage their physical symptoms while supporting psychosocial, emotional, spiritual, and other needs.

When someone first learns they have cancer, it's understandable that they wonder how this diagnosis will affect their lives. How will they tell their kids? Their spouse? Their colleagues or boss? Will they be able to make it to treatments? Will they have enough money to pay for medicine? Will they lose their hair? Ability to have children? Will they die?

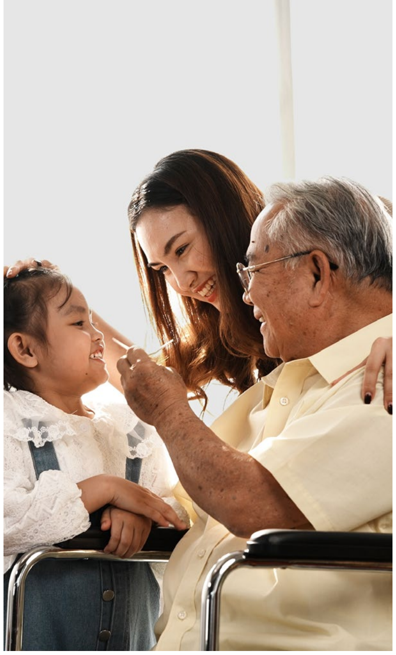
Patients with supportive care concerns are more likely to have a high rate of anxiety or distress. Providing cancer patients access to supportive care services that address their individual needs helps patients optimize their quality of life.

Why Does Supportive Care Matter?

There is mounting evidence that routine integration of social supports can improve the quality of life for cancer patients. One study published in *Cancer Management and Research*[1] found it was crucial and worth whatever effort required to increase social support for lung cancer patients, as it is one of the most critical factors in improving quality of life. The study noted that according to the reviewed studies, "a good quality of life and minimalized symptoms of the disease are much more important for lung cancer patients than the length of their life."

Supportive oncology care uses evidence-based practices to prevent and manage the side effects of cancer treatment. The results translate into better cancer care and improved outcomes, including quality of life, depression, anxiety, health care utilization, and potential survival.

Recognizing that access to quality healthcare is not always equitable, it was important to the SOC to create practice models and tools that can be used in all settings and make them available to everyone.



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[1] Hofman A, Zajdel N, Klekowski J, Chabowski M. Improving Social Support to Increase QoL in Lung Cancer Patients. Cancer Manag Res. 2021;13:2319–2327. Published online 2021 Mar 11. doi: 10.2147/CMAR.S278087. PMID: 33732024; PMCID: PMC7959197.

Hospital and cancer center administrators have found that more holistic supportive care aligns with Commission on Cancer Accreditation standards and supports high-quality care that is guideline recommended.

Through implementing the work of the SOC, some sites have found an increase in patient satisfaction. Many places have used implementations of supportive care screening as a quality improvement project to support accreditation requirements.

What are the Goals of The Supportive Oncology Collaborative?

That cancer patients:

1. Are regularly screened for distress, psychosocial support, and palliative care needs

2. Receive appropriate services (from diagnosis through survivorship and end-of-life) from multiple high-quality service providers that have core competencies in delivering cancer care and support

3. Are informed and empowered, along with their families, by personalized patient care sequence document(s), which are adjusted throughout cancer treatment and supportive care

What is Included in Supportive Oncology?

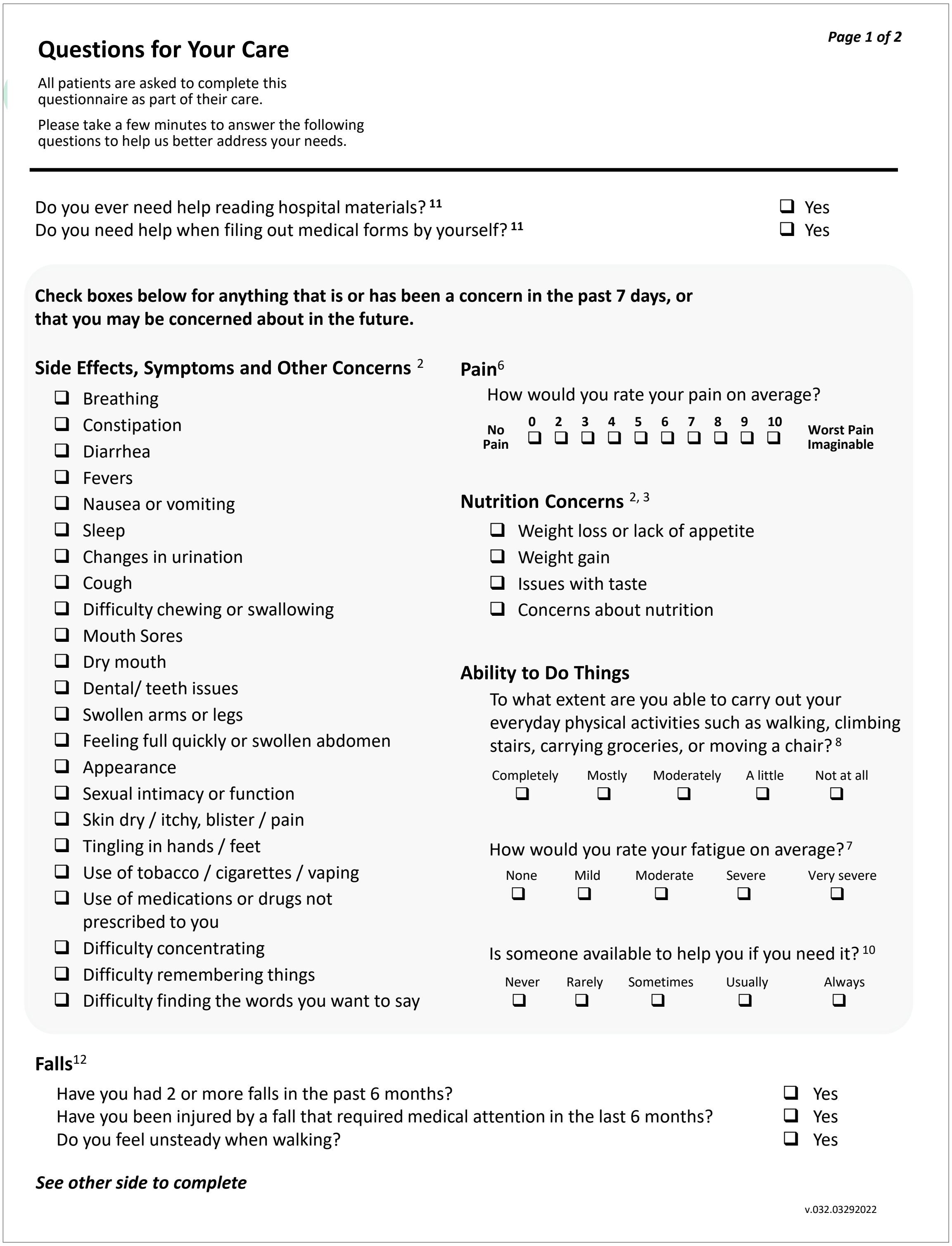
The SOC developed a Supportive Oncology Screening Tool (on the next page) using a compilation of other tools to guide providers in screening adult patients for various care concerns. Reading through the list of questions illuminates the comprehensive set of issues and concerns — physical, emotional, and practical — that can complicate a cancer patient’s journey.

The screening tool was iterated and improved upon through the early stages of the SOC. Subsequently, two more versions were created and implemented for children, in addition to adolescents and young adults. The questions reflect many concerns, including personal, family, environmental, and larger social context issues that impact health. These conditions all affect how well a patient can respond to treatment and enjoy quality of life. Many of these issues would be overlooked in a typical cancer care appointment without the screening tool.

Prior to the work of the Supportive Oncology Collaborative, providers did not have a comprehensive set of community resources and practical guides to help them refer patients to services they might need. The relationships built through the SOC connected providers with community resources and cancer care centers, and these served as the foundation for a comprehensive network of cancer support services in the Chicagoland area.

The SOC created this screening tool for clinicians to use to identify their patient's care concerns. Once identified, the care team can address their concerns and connect the patient to needed resources. The Clinicians repeat the screening at various times throughout a cancer patient's journey.

Figure 3: SOC Adult Screening Tool



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Questions for Your Care

All patients are asked to complete this questionnaire as part of their care.

Please take a few minutes to answer the following questions to help us better address your needs.

Do you ever need help reading hospital materials? [11]	☐ Yes
Do you need help when filing out medical forms by yourself? [11]	☐ Yes

Check boxes below for anything that is or has been a concern in the past 7 days, or that you may be concerned about in the future.

Side Effects, Symptoms and Other Concerns [2]

- ☐ Breathing
- ☐ Constipation
- ☐ Diarrhea
- ☐ Fevers
- ☐ Nausea or vomiting
- ☐ Sleep
- ☐ Changes in urination
- ☐ Cough
- ☐ Difficulty chewing or swallowing
- ☐ Mouth Sores
- ☐ Dry mouth
- ☐ Dental/ teeth issues
- ☐ Swollen arms or legs
- ☐ Feeling full quickly or swollen abdomen
- ☐ Appearance
- ☐ Sexual intimacy or function
- ☐ Skin dry / itchy, blister / pain
- ☐ Tingling in hands / feet
- ☐ Use of tobacco / cigarettes / vaping
- ☐ Use of medications or drugs not prescribed to you
- ☐ Difficulty concentrating
- ☐ Difficulty remembering things
- ☐ Difficulty finding the words you want to say

Pain[6]

How would you rate your pain on average?

	0	2	3	4	5	6	7	8	9	10	
No Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Worst Pain Imaginable**

Nutrition Concerns [2, 3]

- ☐ Weight loss or lack of appetite
- ☐ Weight gain
- ☐ Issues with taste
- ☐ Concerns about nutrition

Ability to Do Things

To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair? [8]

Completely	Mostly	Moderately	A little	Not at all
☐	☐	☐	☐	☐

How would you rate your fatigue on average? [7]

None	Mild	Moderate	Severe	Very severe
☐	☐	☐	☐	☐

Is someone available to help you if you need it? [10]

Never	Rarely	Sometimes	Usually	Always
☐	☐	☐	☐	☐

Falls[12]

Have you had 2 or more falls in the past 6 months?	☐ Yes
Have you been injured by a fall that required medical attention in the last 6 months?	☐ Yes
Do you feel unsteady when walking?	☐ Yes

See other side to complete

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Figure 3: SOC Adult Screening Tool

Please answer these questions to help us address what you need.

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Over the last 14 days, how often have you been bothered by the following problems? [1]	**Not at all**	**Several Days**	**More than half the days**	**Nearly every day**
Feeling nervous, anxious or on edge	☐	☐	☐	☐
Not being able to stop or control worrying	☐	☐	☐	☐
Little interest or pleasure in doing things	☐	☐	☐	☐
Feeling down, depressed, or hopeless	☐	☐	☐	☐

	Never	**Rarely**	**Sometimes**	**Often**	**Always**
Over the last 7 days, I was irritated more than people knew …	☐	☐	☐	☐	☐

Check boxes below for anything that is or has been a concern in the past 7 days, or that you are concerned about in the future.

Practical Concerns [2, 9]

- ☐ Child, adult, and / or pet care issues
- ☐ Paying for food and / or housing
- ☐ Getting to / from treatment (transportation)
- ☐ Work / school
- ☐ Health insurance or no health insurance
- ☐ Paying for medication or medical expenses
- ☐ Being able to live independently or alone

Family/Caregiver Concerns [2]

- ☐ Concerns about my children
- ☐ Concerns about my partner/caregiver/other family
- ☐ Ability to have children

Spiritual / Faith / Religious Concerns [5]

- ☐ Do you struggle with the loss of meaning and joy in your life?
- ☐ Do you have religious or spiritual struggles?

Treatment or Care Concerns [4]

- ☐ I want to better understand my cancer diagnosis or stage.
- ☐ I want to better understand my prognosis or long-term outcome.
- ☐ I have concerns or questions about my treatment options, medication or my plan of care.
- ☐ I need assistance in completing a POA HC (Power of Attorney for Health Care) that allows me to select someone I trust to make medical decisions for me when I am unable to speak for myself.
- ☐ I want to talk with someone about documenting what medical treatments I would, or would not, want to receive if I were approaching the end of my life. (POLST – Practitioner Orders for Life-Sustaining Treatment)

What Matters to You

	Not at all	**Not Much**	**Somewhat**	**Very Much**
Continuing to work at your job or attend school	☐	☐	☐	☐
Knowing the time commitment of your treatment	☐	☐	☐	☐
Doing your hobbies/exercise activities	☐	☐	☐	☐
Maintaining your household responsibilities	☐	☐	☐	☐

Dates of upcoming special events or vacations:

Other problems or concerns [2]:

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*This tool is adapted from: (1) the PHQ-4 developed by Drs. Robert L. Spitzer, Janet B.W. Wiliams, Kurt Kroenke and colleagues; (2) Adapted with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management. © 2022 National Comprehensive Cancer Network, Inc. All rights reserved. The NCCN Guidelines® and illustrations herein may not be reproduced in any form for any purpose without the express written permission of NCCN. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org. The NCCN Guidelines are a work in progress that may be refined as often as new significant data becomes available; (3) Kaiser, M.J., et al., Validation of the Mini Nutritional Assessment short-form (MNA-SF): a practical tool for identification of nutritional status. J Nutr Health Aging, 2009. 13(9): p. 782-8.; (4) Living Well Cancer Resource Center Distress Tool. (5) King, S. D. W., et al. (2017). Determining best methods to screen for religious/spiritual distress. Support Care Cancer (2017) 25:471–479. (6) PROMIS Item Bank v1.0 Pain Intensity Short Form 3a; (7) PROMIS Item Bank v1.0 Fatigue Short Form 4a; (8) PROMIS Item Bank v1.0 Physical Function Short Form 4a; and PROMIS item bank. (9) Live Well At Home Rapid Screen©. (10) PROMIS Item Bank Instrumental Support – Short Form 4a. (11) Cornett, S., (Sept. 30, 2009) "Assessing and Addressing Health Literacy" OJIN: The Online Journal of Issues in Nursing Vol. 14, No. 3, Manuscript 2. (12) Phelan, E. A., Mahoney, J. E., Voit, J. C., & Stevens, J. A. (2015). Assessment and Management of Fall Risk in Primary Care Settings. The Medical Clinics of North America, 99(2), 281–293. http://doi.org/10.1016/j.mcna.2014.11.004

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Office Use Only:

Pt alone	☐
Pt with family	☐
Pt w/ clinician/staff	☐

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Scope and Meaning: The Case for Supportive Oncology

Often the medical community is challenged as guidelines and recommendations are non-specific and leave ample room for variation of processes for care delivery (e.g., distress screening at pivotal points in care and how to provide care to cancer patients beyond treatment).

Dozens of providers responded to the initial call to improve supportive oncology delivery and thus, the SOC was formed. The case for supportive oncology was the result and response to an effort to put processes in place. The guidelines and requirements for certifications existed, but there wasn't a clear process to meet them. Figure 4 below is an example of guidelines from the Commission on Cancer.

> *The Commission on Cancer (CoC) is an accrediting body that establishes standards to ensure quality and comprehensive cancer care delivery in health care settings. Below is a sample of the standards for supportive oncology.*

Figure 4: Commission on Cancer, Program Standards 2012 v 1.2.1: Ensuring Patient-Centered Care

Standard	Description
2.4 Palliative Care Services	Palliative care services are available to patients either on-site or by referral.
3.2 Psychosocial Distress Screening	The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care.
3.3 Survivorship Care Plan	The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated and presented at least annually to the cancer committee and documented in minutes.

4

OBJECTIVES + STRATEGIES OF THE COLLABORATIVE

The Coleman Foundation was founded in 1951 by former Fannie May Candies company entrepreneurs Dorothy and J.D. Stetson Coleman. The Foundation's goal was to create opportunities that empower people to improve their quality of life in the Chicago metropolitan area, no matter their background, circumstances, or zip code. Among the Foundation's tenets was supporting initiatives that give people power over their paths through cancer care and treatment, programs for people with developmental disabilities, and entrepreneurship education.

Why Cancer?

When individuals are diagnosed with cancer, it seems their world has turned upside down, and they're trying to make sense of what lies ahead. Understandably, patients and their loved ones have a lot of questions and concerns. What does their diagnosis mean for their lives and those of their loved ones? How will scheduling appointments and receiving treatment fit into their already busy days? Will they still have enough energy to play with their kids? Will they be able to have children in the future?

IN THE LATE 1990S,* *The Coleman Foundation began increasing funding toward supportive oncology care after noting that services, such as nutritional support, counseling, and psychosocial care following cancer treatment, directly benefit cancer patients.

"As expected, a cancer diagnosis triggers anxiety, depression, and distress for patients and their families," said The Coleman Foundation's former president Michael Hennessy. "Quality care requires treating the whole patient, not just their cancer — and members of the Supportive Oncology Collaborative are making important strides in improving care bringing in additional providers of the services patients and their caregivers need."

While the benefits of supportive care are apparent, many Chicago-area patients and families lack access to services and struggle with unmet needs.

GIVING PEOPLE CONTROL OVER THE THINGS THEY CAN CONTROL DURING CANCER TREATMENT

The Foundation noted the gap in supportive care was two-fold:

- Cancer care providers did not know how to implement or fund the programs, and
- There was a lack of collaboration in cancer treatment among Chicagoland area hospitals and community providers.

When the Institute of Medicine (IOM) released its landmark report in 2013, it recommended supportive oncology services (e.g., distress, psychosocial, pain management, nutrition, palliative, survivorship, and end-of-life care) from diagnosis through end-of-life. Most cancer centers recognized a gap between the services their patients needed and the medical services they provided, but they didn't know how to bridge that gap.

> *The Coleman Foundation recognized the time was right to capture the momentum and build upon years of cancer care funding and grantee relationships.*

As a result, The Coleman Foundation created goals in April 2014 to guide the overall initiative. Those goals were informed by the Foundation's experience with existing cancer programs and services, as well as recommendations in the IOM 2013 report.

The goals were that cancer patients:

- Are regularly screening for psychosocial/distress support and palliative care needs,
- Receive all services identified by distress and palliative care screenings (from diagnosis through survivorship and end-of-life) from a collaboration of multiple high-quality service providers with core competencies in delivering cancer care, and
- Are informed and empowered, along with their families, by the personalized patient care sequence document(s), which are adjusted throughout cancer treatment and supportive care

> *Though no small task, the cancer centers in the region knew they needed to find a way to provide all their cancer patients with access to appropriate supportive care and referrals to services they need during their cancer journey.*

The Coleman Foundation had years of experience funding cancer support services and deepening relationships with a diverse spectrum of providers. These grantees were receptive to joining the Supportive Oncology Collaborative and readily agreed to participate.

Identifying what cancer care providers need to fulfill IOM recommendations

The Coleman Foundation hired a professional team from the Center for Business Models in Healthcare to lead the initiative.

The Centers for Business Models in Healthcare began by examining what community institutions needed for the entire care team to implement the IOM recommendations and provide the supportive care patients deserved. They held structured discussions between May and June 2014 and a large workshop in June 2014.

The Coleman Foundation invited practitioners from the private, public, safety net, Veterans Affairs, community hospitals, and medical centers to join the Supportive Oncology Collaborative. With a focus on health equity, the goal was to ensure the solutions created by the Supportive Oncology Collaborative would work across the continuum of care and in all types of settings.

Next, Centers for Business Models in Healthcare surveyed 35 institutions, which included 13 cancer centers, 14 stand-alone cancer support centers, and eight hospice organizations. They asked them to rank their top five from a list of 27 supportive oncology project ideas.

Providers wanted to work together to develop solutions their respective centers could use. To do so meant they needed to be intentional about creating process improvements that would be implementable in various settings. They also had to create measurable tools that could demonstrate effectiveness and make a concerted effort to identify all of the community-based resources for their patients.

> *"It's about knowing resources in your community. It's acting on your own behalf...and having the knowledge to do that."*
>
> — Mike Hennessy, former president and CEO of the foundation

Here are the top ten project ideas that were collectively identified by meeting participants.

Figure 5: Top 10 Project Ideas in Rank order (from Survey of 35 organizations)

Cancer Patient Focused	
Delivery of Services	Develop a "tiered" care process and pathways which stratify patients by type and extent of **distress and supportive** care need, and direct patients to an appropriate provider based on need.
Delivery of Services	Develop a "tiered" care process and pathways which stratify patients based on their **palliative** needs, and facilitates care by appropriate providers. Treating physicians/staff address more basic needs; more complex cases are referred to palliative specialists.
Delivery of Services	**Hospice** — Develop a better care model/pathway for identifying patients for hospice and delivering multi-disciplinary services based on needs. Expand hospice services outside of the 6-month hospice window.
Delivery of Services	Develop a care process and pathways for **survivors** based on their needs.
Screening tools and processes	Develop consolidated, adaptive tool(s) for various patients and stages of screening, using **validated distress and palliative screening tools.**
Financial	Work with payers as a coalition to **address reimbursement** for distress, palliative, supportive, hospice, caregiver and related services
Educate	Develop patient education on **what being a survivor means.**
Financial	Financial work with hospital administrators as a coalition (in parallel with the payer/reimbursement effort), **to ensure distress, palliative, and related services are appropriately offered.**
Reporting and Metrics	Develop **metrics** that work in both inpatient and outpatient cancer setting that can be consistently applied initially and at pivotal points of care. Develop **databank of local/regional metrics.** Develop benchmarks.
Educate	**Develop training on screening** for palliative, distress, fatigue, financial distress, pain needs.

Three Projects Became the Focus of the SOC’s work

As a result of the exploration process, three project ideas were identified, and this became the focus of the Supportive Oncology Collaborative’s work:

1. *To improve local inter-institutional collaboration by leveraging respective resources and facilitating care consistency across sites*
2. *To develop stratified care processes that identify appropriate providers based on patient needs*
3. *To improve the reimbursement of supportive oncology services*

Since the entire interdisciplinary care team is involved in providing supportive care, The Supportive Oncology Collaborative included: nurses, social workers, clergy, doctors, physician assistants, nurses aids, nurse navigators, and cancer support center staff.

Patient-Centered Care Objectives

The Supportive Oncology Collaborative’s objective from the patient-centered experience was to improve the quality of care, which involved strengthening professionals’ abilities to:

- Clarify diagnosis, prognosis, and treatment plans
- Address concerns that affect day-to-day life
- Complete treatment while managing side-effects
- Explore and document medical and care wishes

The Overwhelming Need to Support *All* Aspects of a Cancer Diagnosis

The need for supportive cancer care isn’t new, but admittedly, a baseline didn’t exist. Clinicians were not equipped in dealing with the other aspects of a cancer diagnosis because many hospitals and cancer centers didn’t have the resources, staff, or funds to help patients access the psychological, social, and emotional supports they needed.

Clinicians agreed that providing supportive oncology care is the right thing to do, but no one knew HOW to do that in their setting.

As a result, many cancer patients were not getting the services and resources they needed, and The Coleman Foundation spearheaded an initiative to incorporate supportive oncology into comprehensive cancer care.

The Coleman Foundation funded institutions to participate in the Supportive Oncology Collaborative and provided funding to implement the tools and practices at various clinics within the hospital or cancer center. To ensure that the practice models could work anywhere, and with an intent to provide equity in access to services, the implementation sites included safety net, community, VA, and public hospitals, as well as academic medical centers. They also included both general and specialized cancer clinics.

> *"Equity requires a reduction in the variability of care regardless of where the cancer is treated. It's imperative to follow evidence-based guidelines for treating the patient's entire set of needs. The SOC screening tools, follow-up documents, and practice models are now being implemented across the region and in institutions across the US, and patients are benefiting."*
>
> — SOC facilitator Christine Weldon, Adjunct Instructor, Northwestern University Feinberg School of Medicine and Managing Director, Center for Business Models in Healthcare

Supportive Oncology Collaborative Adult Program Grantees

November 2014

Implementation Grants

John H. Stroger, Jr. Hospital of Cook County

Mercy Hospital and Medical Center

Rush University Medical Center

Sinai Health System

University of Chicago Medical Center

University of Illinois Hospital & Health Sciences System

Design Process Teams participation grant

Equal Hope

NorthShore University HealthSystem

Northwestern University

November 2016

Chicago Association for Research and Education in Science (CARES) for Jesse Brown VA Hospital

Equal Hope

John H. Stroger, Jr. Hospital of Cook County

Loyola University Medical Center

Mercy Hospital and Medical Center

Methodist Medical Center of Illinois

Rush University Medical Center

Sinai Health System

University of Chicago Medical Center

University of Illinois Hospital & Health Sciences System

Northwestern University

July 2018

Chicago Association for Research and Education in Science (CARES) for a project at Jesse Brown Veterans Medical Center

Loyola University Medical Center

Methodist Medical Center of Illinois

Sinai Health System

September 2021

Sinai Health System

Chicago Association for Research and Education in Science (CARES) for a project at Jesse Brown Veterans Medical Center

Little Company of Mary (Order of St. Francis)

Addressing the Unique Needs of Patients

Through this intense process and reflection, working groups identified that facing cancer looks different for adults than it does for young adults, and different again for children. What is essential or relevant to a pediatric patient won't be the same as someone who is undergoing treatment in their sixties. A newlywed with hopes to have children won't have the same concerns as someone who is past menopause. Tools and resources were needed to address the unique needs of different patient populations and cancers unique to those patients.

The initiative began with the Adult Supportive Oncology Collaborative.

Then, in 2017, The Coleman Foundation expanded its reach and initiated a Pediatric Supportive Oncology Collaborative to better support care service delivery for children and their families.

The SOC didn't stop with adults and children. Members of the Collaborative recognized that adolescents and young adults with cancer have their own unique set of concerns, and in 2019, The Coleman Foundation initiated the Adolescent and Young Adult Supportive Oncology Collaborative to identify and address their supportive care concerns.

Figure 6: Three Supportive Oncology Collaboratives Address Needs of Different Populations

Figure 7: Adult SOC Objectives

That all cancer patients:

1. Are regularly screened for distress, psychosocial support and palliative care needs
2. Receive appropriate services (from diagnosis through survivorship and end-of-life) from multiple, high- quality service providers that have core competencies in delivering cancer care and support
3. Are informed and empowered, along with their families, by personalized patient care sequence document(s), which are adjusted throughout cancer treatment and supportive care

Figure 8: Adolescent and Young Adult and Pediatric SOC Objectives

The Supportive Oncology Collaboratives for children and for adolescents and young adults worked together to:

1. Develop a common set of tools to screen for distress throughout the cancer journey
2. Develop a comprehensive list of services based on screenings to help patients and their families access support
3. Educate providers, patients, and payers about benefits of psychosocial screening and service provision
4. Share findings and tools, and disseminate project results

Pediatric Collaborative

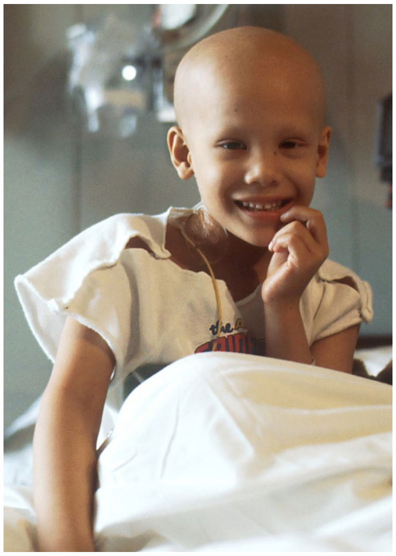
About 9,910 children in the United States under 15 will be diagnosed with cancer in 2023. According to the American Cancer Society,

85% OF CHILDREN WITH CANCER
now survive five years or more, thanks to significant treatment advances in recent decades.

The Supportive Oncology Collaborative for Children with Cancer consisted of clinicians from seven Chicagoland cancer programs. The Collaborative focused on improving the assessment and delivery of psychosocial and supportive care to children with cancer and their families. The clinicians participating in the Collaborative encourage assessment at the time of diagnosis and throughout the treatment journey so that services are available to help alleviate issues during treatment, post-treatment surveillance, and through the transition into survivorship.

Specifically, the Pediatric Supportive Oncology Collaborative sought to:

- Improve pediatric and adolescent supportive oncology service delivery;
- Contribute to understanding the landscape of pediatric and adolescent supportive oncology practices across Chicagoland cancer providers;
- Identify opportunities for improvement through shared tools, methods, and organizational improvements; and
- Provide additional education on supportive oncology for pediatric clinicians.



The following Chicago area hospitals received implementation grants to participate in the the Pediatric Supportive Oncology Collaborative:

November 2015

Ann & Robert H. Lurie Children's Hospital of Chicago

Rush University Medical Center

University of Chicago Medical Center

June 2017

Advocate Children's Hospital

Ann & Robert H. Lurie Children's Hospital of Chicago

John H. Stroger, Jr. Hospital of Cook County

Loyola University Medical Center

Rush University Medical Center

University of Chicago Medical Center

University of Illinois Hospital & Health Sciences System

Adolescent and Young Adult Collaborative

OVER 70,000 ADOLESCENTS AND YOUNG ADULTS (AYA), *ages 15 to 39, are diagnosed with cancer in the U.S. each year, according to the National Institutes of Health.*

These young people live with the long-term effects of cancer treatment, including cognitive effects, cardiac issues, secondary cancers, and psychosocial impacts. While AYA patients have some psychosocial support when they start treatment, as they move into the surveillance phase of care, there is little help to navigate the cancer journey. The focus of this initiative was to address how clinicians and patients transition from treatment to survivorship and to help patients achieve the best possible quality of life.

Cancer centers at the following institutions received grants to implement Supportive Oncology for Adolescents and Young Adults with Cancer:

November 2019

Advocate Lutheran General Hospital

Advocate Children's Hospital

Northwestern Medicine

Ann & Robert H. Lurie Children's Hospital of Chicago

Rush University Medical Center

Rush University Children's Hospital

University of Chicago Medicine

Comer Children's Hospital

The Power and Reach of the Supportive Oncology Collaborative

The SOC aims to assess and deliver psychosocial and psychological support to cancer patients and their families from diagnosis throughout their cancer journey and beyond to survivorship.

Quite simply, it puts patients first and encourages patient-centered care.

It also empowers professionals who touch the lives of each patient.

After implementing the SOC tools and practices and acknowledging the improvement of supportive care delivery across several institutions, key SOC partners were ready to engage in a process to propel treatment and proper pairing of care events with services. Thus, The Coleman Foundation supported the healthcare providers in receiving training in a method known as the 4R Oncology Model.

4R Oncology® is a patient-centered approach that emphasizes providing patients with a care sequence plan at diagnosis. It empowers patients with information and knowledge to understand their cancer journey. 4R Oncology was developed in 2008 by Christine Weldon, MBA, and Julia Trosman, Ph.D. of the Center for Business Models in Healthcare (CBMHC), and clinicians at Northwestern University. CBMHC has introduced the 4R model to multiple cancer centers nationally, and with the support from The Coleman Foundation, the model was implemented at several Chicago area healthcare institutions.

This care sequence plan uses project management principles to guide the patient and care team throughout the cancer care continuum. The 4R Care Sequence® provides a patient with the information they need to manage, sequence, and schedule critical tasks with the support of an informed oncology team. The 4R care sequence plan also helps patients and families more fully understand their treatment and what to expect at each stage in the care continuum.

The following institutions received funding to train clinicians and implement the 4R Patient care sequence model:

November 2018

Lake Forest Hospital

Northwestern University

Rush University Medical Center

University of Chicago Medical Center

University of Illinois Hospital & Health Sciences System

Advocate Sherman Hospital

NorthShore University HealthSystem

Strategic Communication Objective

The Supportive Oncology Collaborative aimed to increase patient access to supportive care services by leveraging data and stories from implementation sites to influence stakeholders. To do this, they hired Amdur Spitz & Associates to develop clear messages, use data and evidence in storytelling, and build a variety of communication channels to influence stakeholders. They worked closely with the Centers for Business Models in Healthcare and Coleman Foundation staff, and served as the communication team for the initiative from 2016 to 2021.

On behalf of the SOC, Amdur Spitz & Associates partnered with SOC member institution's marketing and communications teams and patient advocacy groups to amplify SOC stories through internal communications and digital channels. Raising the profile of the initiative within participating institutions helped to build support among administrators and other institutional gatekeepers.

The SOC emphasized the importance of collecting data on the benefits of supportive oncology services. SOC members published abstracts and posters in peer-reviewed journals. SOC members told transformative stories about implementing supportive oncology services in their clinics, and these stories were published in oncology trade journals like CURE and Oncology Today. The communications team publicized these accomplishments to help persuade healthcare policymakers, administrators, and decision-makers to expand supportive care screenings to all cancer patients, and to provide referrals to supportive care services.

5

HOW THE SUPPORTIVE ONCOLOGY COLLABORATIVE WORKED

Starting with a Deep History and Longstanding Relationships

After years of funding cancer support organizations, The Coleman Foundation built an informal network. They engaged this network to identify needs and explore ways to connect patients and families to resources systematically. The Foundation partnered with the Center for Business Models in Healthcare and Amdur Spitz & Associates, Inc. to facilitate the collaboration, draft the materials, and expand the work beyond individual site locations.

Furthermore, with the network in place, the Foundation knew it could make a difference in the lives of thousands of patients and caregivers in the Chicagoland area. The Coleman Foundation provided crucial funding to get the Supportive Oncology Collaborative organized and running because the Foundation knew that with a strategy, people to lead the effort, and a commitment to support and communicate the hard work, the impact could be felt as widely as possible and replicated across cancer centers throughout the country.

Physicians and Clinicians

Taking the lead from physicians and clinicians, the Collaborative put systems in place to ensure everything they worked on and developed was clear, systematic, and measurable. The Collaborative set up Working Groups to tackle specific issues.

Hospitals and healthcare practitioners knew they needed a different model of supportive oncology care. They didn't know where to access the resources or have the funds, time, or people to develop a process to improve patient care by including supportive oncology alongside treatment.

According to the Institute of Medicine (IOM) report, "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis," supportive care for cancer patients and their families should start at diagnosis and continue through the entire care continuum.

HELPING CANCER PATIENTS TO LIVE BETTER

> **PATIENTS WITH SUPPORTIVE CARE CONCERNS**
> *are more likely to have a high rate of anxiety or distress. Not finding better ways to improve cancer care and supportive services was not an option.*

The Coleman Foundation engaged the Center for Business Models in Healthcare to facilitate the process of identifying and leading collaborative projects. The Center employs business transformation and process improvement methodologies to address the challenges faced by the healthcare system. The methods applied in a program approach are effective when new expectations or requirements are added to entrenched practices.

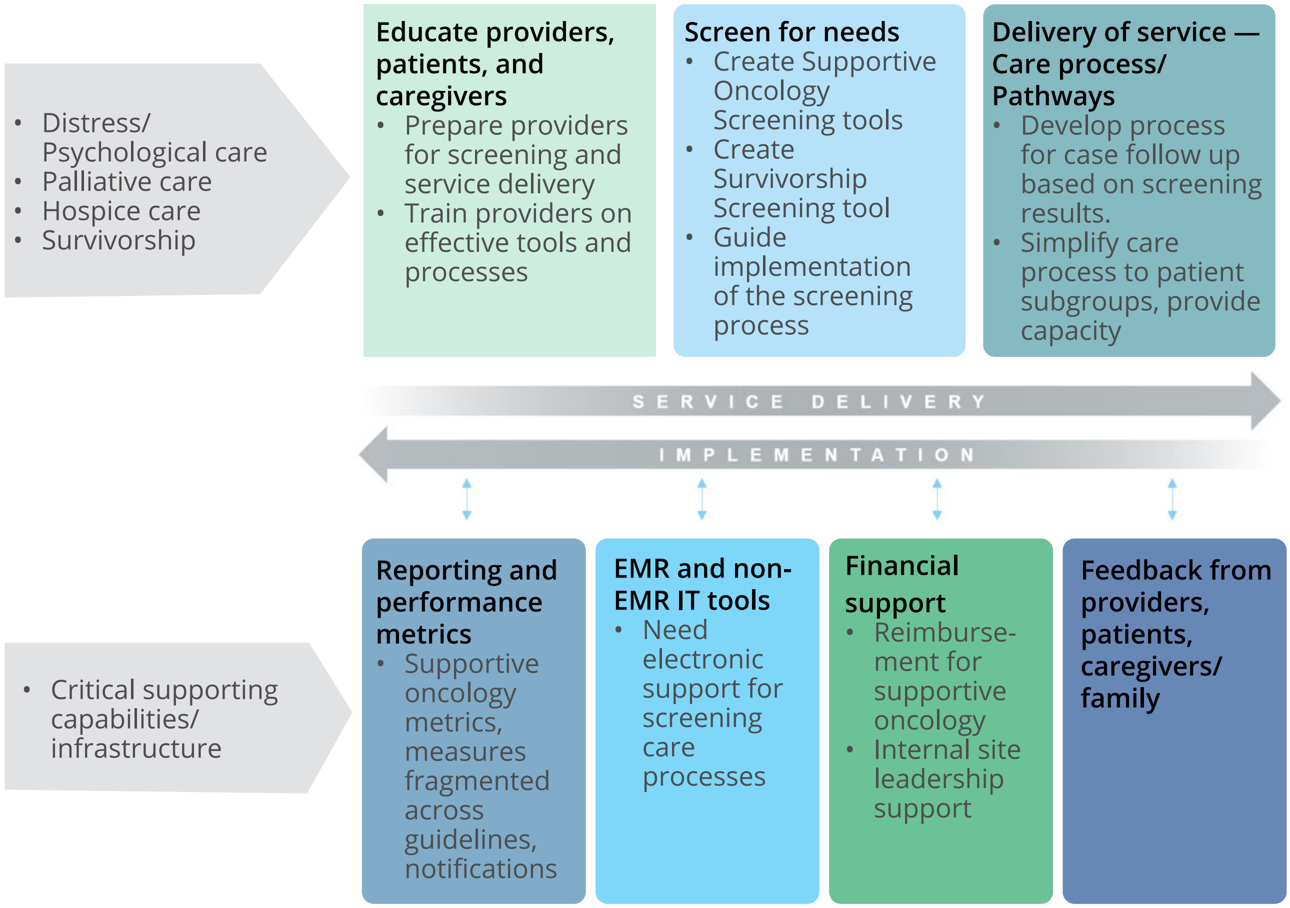
The first meeting convened to assess the landscape of supportive oncology services provided by Chicago hospitals, cancer support centers and hospice organizations. The group included over 100 Chicago area cancer stakeholders.

This group met in 2014 and generated 27 project ideas. After the assessment and analysis, The Center for Business Models in Health Care grouped those 27 projects into seven priorities and designed a program approach for service delivery and implementation as shown in the diagram below.

The Collaborative created Working Groups to address the priorities identified. Each Working Group met to review the current state of the area they were focused on and discussed the most critical issues they could address. Working Groups were facilitated regularly, with a mix of in-person and web-based calls meeting monthly or quarterly depending on the group's work.

Additionally, the Working Groups needed a way to organize the prioritized projects into an overall program. The diagram below shows how the working teams would approach what needed to be done. The top row includes activities that support service delivery, and the bottom row includes critical support capabilities and infrastructure that needed to be in place to support the service delivery.

Figure 9



- Distress/ Psychological care
- Palliative care
- Hospice care
- Survivorship

Educate providers, patients, and caregivers
- Prepare providers for screening and service delivery
- Train providers on effective tools and processes

Screen for needs
- Create Supportive Oncology Screening tools
- Create Survivorship Screening tool
- Guide implementation of the screening process

Delivery of service — Care process/ Pathways
- Develop process for case follow up based on screening results.
- Simplify care process to patient subgroups, provide capacity

- Critical supporting capabilities/ infrastructure

Reporting and performance metrics
- Supportive oncology metrics, measures fragmented across guidelines, notifications

EMR and non-EMR IT tools
- Need electronic support for screening care processes

Financial support
- Reimbursement for supportive oncology
- Internal site leadership support

Feedback from providers, patients, caregivers/ family

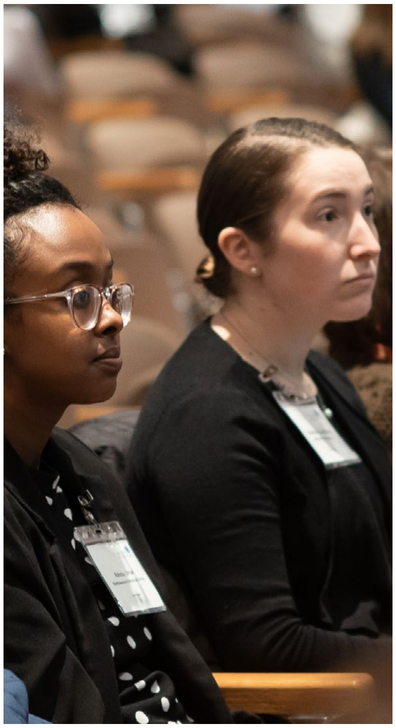
The chevrons on the left in Figure 9 highlight the five Working Groups: distress/psychological care, palliative care, hospice care, survivorship, and critical supporting capabilities/ infrastructure. Each Working Group addressed one of the three categories of Service Delivery, noted at the top of the Figure 9, including: provider and patient education, screening of needs, and care processes. They identified what needed to be done in each area to create the conditions in a healthcare practice that would enable them to implement supportive care screening and referral services systematically.

To address the education gap, SOC participants created 26 courses to educate and train providers on using practical tools and processes to provide supportive care. This approach included utilizing the screening tool created by the SOC and implementing the instrument during the patient's appointment.

The boxes at the bottom of Figure 9 outline the components of infrastructure for implementing supportive care. Measuring improvements was an important piece of the work, and this required reporting of performance metrics. Plus, the supporting capabilities included infrastructure updates to ensure the work continued.

The project facilitators worked with each implementation site to streamline efforts based on consistency, relevance, effectiveness, standard methodology, and project management. The functions of this core program support included:

- Assisting teams in applying standard approaches to care process design and development, such as templates and examples to complete their work
- Researching metrics with quality improvement organizations; identifying relevant, feasible metrics required or anticipated by certification bodies
- Supporting assessment of current processes, in comparison with optimal processes and collection of metrics
- Assuring and managing alignment of key elements of the design process, teamwork implementation, site work, as well as collecting and analyzing data reported by Collaborative sites
- Consulting teams on challenges and barriers that may impact the accomplishment of their goals



Improving Processes at Cancer Clinics

The Coleman Foundation's initial grants for the Supportive Oncology Collaborative supported a systemic approach to process improvements developed by the Center for Business Models in Healthcare. Grant awards were made to hospitals and medical centers for interdisciplinary supportive care teams to participate in designing process improvements and in cross-site Design Teams.

These Design Teams were tasked with implementing process improvements for the delivery of supportive oncology, including utilizing distress screening tools and refining a process to refer patients to services at their sites or community resources.

These Design Teams included representatives from different roles on the care team (e.g., physicians, PAs, nurses, social workers and nurse navigators) and representatives from different care settings (e.g., academic, community, public, safety net or veteran administration institutions), and the teams discussed how they address specific issues at each institution.

Design Teams also organized into several cross cancer program "Working Teams" to address Distress/Emotional support, Geriatric Oncology, Advanced Disease, Cancer Center Administration, and many others.

Working Across Institutions to Improve Patient-Centered Care and Equity in Access

The culture of the SOC was about patient-centered care and equity in access to supportive care. Clinicians laid down their institutional shields and worked together. While the multidisciplinary teams of oncology care professionals implemented process improvements at their own institutions, they found inspiration from one another.

They discussed hard issues and problem-solved together.

Working Groups

Working Groups were an important part of how the Supportive Oncology Collaborative functioned. Working Groups were designed to tackle specific challenges. Each Working Group comprised a mix of roles and different settings (e.g., types of cancer centers, support programs, supporting services at hospitals, and advocacies). They came together to identify what they needed to provide the best possible care for their patients and address different patient concerns. The diversity of perspectives in terms of their roles in patient care and the healthcare settings where they practiced added to the richness of conversation, experience, and problem-solving ability.

The SOC Working Groups identified challenges they faced in their practices daily, issues they wanted to address more effectively and efficiently, and looked for ways to create access to supportive care for cancer patients no matter where they were receiving care.

While the Working Group areas of focus evolved throughout the initiative, below are examples of Working Groups and what they were able to produce and accomplish with SOC funding.

Design Working Group — Emotional Team

Accomplishments:

- Cancer support centers developed a presentation of community resources, which they shared with hospital staff at all SOC sites.
- Created a tri-fold brochure of community resources with customized information specific to each site.
- Created the Journey Connections resource list. Then updated and simplified it into a spreadsheet that could be easily sorted to identify resources for a patient. This list was later added to the SOC website and tagged for easy sorting.
- The SOC then partnered with Aunt Bertha's and contributed the full set of resources for their Chicago database. AuntBertha.com has since been re-branded to Findhelp.com, and the database continues to be updated and available free of charge.
- Created a guide for oncologists to refer cancer patients to a psychologist and/or a psychiatrist.

Design Working Group — Geriatric Team

Accomplishments:

- Created a summary document of Life Expectancy Tools for use by treating clinicians.
- Drafted a tumor board checklist for use with geriatric cancer patients to ensure their unique needs are considered.
- Created guidance documents, "Increase Awareness of Geriatric Considerations for Treating Clinicians" and "Geriatric/Frailty Considerations or Cancer Patients/Families."
- Created a "What is Delirium?" handout for cancer patients and families.

Design Working Group — Advance Disease Team

Accomplishments:

- Created a "Can You Plan for Everything" brochure for cancer patients with advanced disease and a companion brochure for caregivers/family members called "Can You Help Someone Plan for Everything." The brochures provide personal and practical considerations for patients facing uncertainty due to their disease trajectory.
- Rolled out the "Cancer Take Charge Card" in two versions: one for chemotherapy and another for immunotherapy. Cards are customized with information specific to each cancer treatment site.
- Surveyed 82 hospice agencies in the Chicagoland area to collect information about their hospice services and, if available, palliative services and distributed the list through the SOC.
- Created a guidance document for sites with capacity constraints for outpatient specialty palliative care, "Palliative Care in an Outpatient Treatment Environment."

Design Working Group by cancer type

Beginning in 2019, as the conversation evolved toward patient communication, a new set of Cross-Site Working Teams was organized by disease category, such as Breast, Colorectal, Lung, etc. These teams discussed supportive care and patient communication.

They began to create 76 patient self-management tools. Clinicians utilized these patient handouts in their clinics during appointments. The self-management tools were categorized and made available on the SOC website. They are now available on the Equal Hope website.

Key Factors That Contributed The SOC's Success

- The leadership team from each cancer program actively agreed with the overall objectives of the Supportive Oncology Collaborative.
- Each meeting started with reviewing the objectives of the Supportive Oncology Collaborative. The work was aligned with those objectives.
- Cross-cancer program "Working Teams" focused on specific areas all the cancer programs wanted to improve.
- Working Teams included experts from outside the grantee cancer sites and national cancer organizations to provide additional insights.
- A mixture of academic, community, and safety net cancer programs was represented in each of the Working Groups, Design Teams, and Working Teams. They all have different practices and approaches, which provided an opportunity to learn new ways of supporting patients.
- Neutral facilitators who worked both with the cancer centers and the Working Groups were able to prompt areas of discussion when consistent issues existed across the cancer programs.
- Funding supported the project so the clinicians and allied health professionals could spend dedicated time on the project.

Convenings

The Supportive Oncology Collaborative gathered at least once yearly for a large in-person meeting. These all-day meetings were an essential part of relationship-building and information sharing. All of the SOC member organizations' staff were invited to participate. Agendas for the sessions included presentations from the Work Groups, Design Teams, and Working Teams. The meetings also addressed broad agenda items, such as survivorship care planning, a template for how to advocate for more supportive care headcount, and a discussion of how to replicate the work of the Supportive Oncology Collaborative beyond the participating institutions.

Discussions were robust and fruitful. A comment from the floor at one of these gatherings sparked the group to form a special Pediatric Supportive Oncology Collaborative and Young Adult and Teens Supportive Oncology Collaborative.

Payer Reimbursement Facilitation

The approach to improving the delivery of supportive oncology didn't end with creating tools and resources, and practice models. Once the evidence showed this work helped improve the quality of life and care for patients, The SOC needed to help make the financial model work for the healthcare providers.

Improving reimbursement rates requires time and deliberate, planned effort. Therefore, the reimbursement team worked with the design and process improvement teams to understand what reimbursement methods were being used and where there were gaps. They put together a list of billing codes that insurance companies currently approved and are applicable to supportive care services. They also held meetings to discuss billing options and met with payers.

Helping institutions to identify billable services and incorporate the correct billing codes into the electronic medical record system ensures the services would be recorded and all of the eligible ones are reimbursed. This goes a long way toward making supportive care services sustainable. In addition, they collected data and metrics on the quality and performance of supportive oncology services. That information supported discussions about reimbursement with payers and health system leaders.

Unless a service can be billed and reimbursed, it's terribly tricky for healthcare institutions to adopt change. Getting through the bureaucracy to introduce new billing codes to the electronic health record systems is also a challenge. Yet healthcare providers knew this is what had to happen to be able to provide the care and services patients need, and they worked to get the changes made in their institutions.

> *Healthcare providers and busy medical practices find it challenging to offer additional care if a service takes time but isn't billable.*

For example, what if a patient is feeling depressed or anxious because they're not able to complete their work or school assignments due to their cancer care? Or, they're masking their depression by engaging in unhealthy habits like excessive drinking? Unless a healthcare provider feels confident that they can provide assistance, they might be reluctant to ask how their patient handles stress. Yet, a patient's mental health could make a big difference in how that patient and their family fare, not to mention their overall health outcomes.

By adding those billing codes to their system, healthcare providers could do the work needed while allowing their healthcare institutions to get reimbursed. In fact, by using applicable billing codes for supportive care, one small clinic at a safety net hospital was reimbursed $20,000 over 12 months by insurance, and one medical center could have billed $400,000 in a year had they used the billing codes.

Supportive Oncology Collaborative Participating Institutions

Advocate Health Care

NM / Cadence Health

The Cancer Support Center

Cancer Wellness Center

Community Cancer Center

Gilda's Club Chicago
An Affiliate of the Cancer Support Community

Home of Hope
Cancer Wellness Center

Hult Center
for healthy living

Cook County Health & Hospitals System
CCHHS

JourneyCare Hospice
— An Addus HomeCare Company —

LivingWell
Cancer Resource Center

1870 Ad Majorem Dei Gloriam
Loyola Medicine

Mercy
Mercy Hospital & Medical Center

UnityPoint Health
Methodist | Proctor

NorthShore
University HealthSystem

Northwestern Medicine

Rush University Medical Center

Sinai
Sinai Health System

Swedish Covenant Hospital
The science of feeling better

The University of Chicago Medicine

University of Illinois
Hospital & Health Sciences System
Changing medicine. For good.

Wellness House for Living with Cancer
You'll feel better inside.

Ann & Robert H. Lurie
Children's Hospital of Chicago

At the forefront of Kids' medicine
UChicago Medicine
Comer Children's

Almost Home Kids
Share the Care

UI Health UIC

Advocate Children's Hospital

GIPPCC
Greater Illinois Pediatric Palliative Care Coalition

CARES
Chicago Association for Research and Education in Science

Jesse Brown VA Hospital

Rush University Children's Hospital

equal hope

Advocate Sherman Hospital

OSF HealthCare
Little Company of Mary Medical Center

Advisory Team

American Cancer Society

ASCO
American Society of Clinical Oncology

City of Hope

Healing Pathways
Cancer Resource Center

Leukemia & Lymphoma Society

Livestrong Foundation

6

BUILDING TOOLS, RESOURCES, AND AN EVIDENCE BASE

> *Building a movement means building the infrastructure to help the movement be sustainable, accessible, and replicated. It needs to be proven it can work.*

The Supportive Oncology Collaborative (SOC) has developed and piloted screening tools, associated practice reference documents, and provider training courses that meet or exceed recommended supportive oncology standards set by national organizations. The training and tools developed as a result of the collaboration were all done with one goal: to support the work of multi-disciplinary teams to deliver supportive care for cancer patients.

When physicians and healthcare professionals began working together, with the guidance and support of The Center for Business Models in Healthcare (CBMHC), they convened the stakeholders who could develop the necessary tools and resources to address patients' concerns and overcome barriers to providing that care. It all had to be done in ways that could measure and demonstrate impact so a wide range of institutions could apply them with equal success.

This was an essential step for the Collaborative. To persuade healthcare professionals to implement new processes for service delivery, the SOC needed to clearly document actionable, replicable, and objective strategies and demonstrate a positive impact in the lives of cancer patients and their families.

Tools and Resources Developed by the Supportive Oncology Collaborative

8 patient distress and supportive needs screening tools

51 physician resource documents

26 professional training videos for continued medical education credit

60 abstracts and presentations for publications

73 patient self-management handouts, with links to verified resources

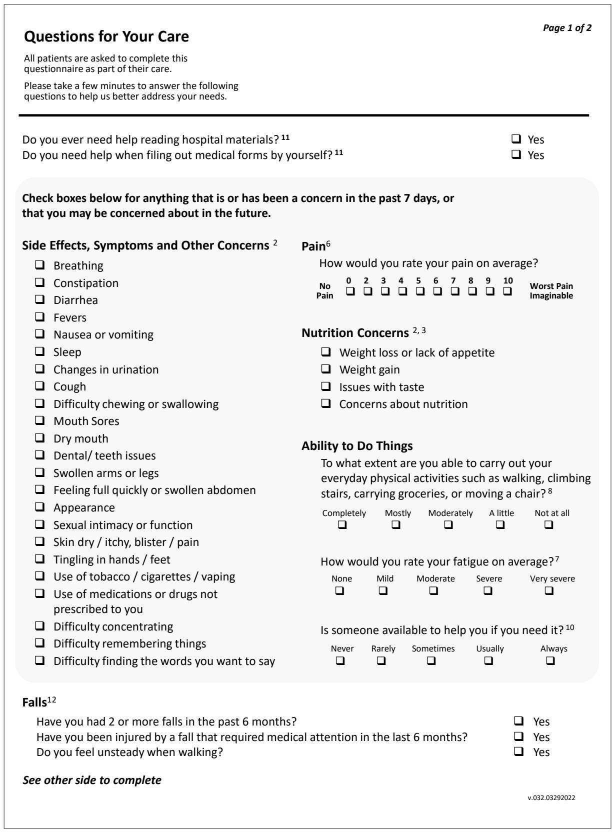
Comprehensive Tool Kit designed for cancer centers to provide ongoing quality improvements in Supportive Oncology Care

Cancer Take Charge Card customized for patient and treatment site

Supportive Oncology Collaborative — Jointly Created Tools And Resources

Supportive Oncology Screening Tool

The Supportive Oncology Collaborative conducted an exhaustive review of existing screening tools across all aspects of supportive oncology care. Reviewing literature and guidelines, the SOC teams developed a comprehensive supportive oncology screening tool based on validated tools and adaptations of other standard tools. This screening tool has been piloted, tested, and refined across a dozen institutions. The supportive oncology screening tool responses guide patient appointments with treating clinicians and inform the social support team (usually a social worker) of the patient's psychosocial and practical concerns. The tool is available at no cost in English, Spanish, Mandarin, and Polish. The SOC also created Pediatric and Adolescent and Young Adult versions of the screening tool, which are available in English and Spanish.



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Questions for Your Care

All patients are asked to complete this questionnaire as part of their care.

Please take a few minutes to answer the following questions to help us better address your needs.

Do you ever need help reading hospital materials? [11]	☐ Yes
Do you need help when filing out medical forms by yourself? [11]	☐ Yes

Check boxes below for anything that is or has been a concern in the past 7 days, or that you may be concerned about in the future.

Side Effects, Symptoms and Other Concerns [2]

- ☐ Breathing
- ☐ Constipation
- ☐ Diarrhea
- ☐ Fevers
- ☐ Nausea or vomiting
- ☐ Sleep
- ☐ Changes in urination
- ☐ Cough
- ☐ Difficulty chewing or swallowing
- ☐ Mouth Sores
- ☐ Dry mouth
- ☐ Dental/ teeth issues
- ☐ Swollen arms or legs
- ☐ Feeling full quickly or swollen abdomen
- ☐ Appearance
- ☐ Sexual intimacy or function
- ☐ Skin dry / itchy, blister / pain
- ☐ Tingling in hands / feet
- ☐ Use of tobacco / cigarettes / vaping
- ☐ Use of medications or drugs not prescribed to you
- ☐ Difficulty concentrating
- ☐ Difficulty remembering things
- ☐ Difficulty finding the words you want to say

Pain[6]

How would you rate your pain on average?

	0	2	3	4	5	6	7	8	9	10	
No Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**Worst Pain Imaginable**

Nutrition Concerns [2, 3]

- ☐ Weight loss or lack of appetite
- ☐ Weight gain
- ☐ Issues with taste
- ☐ Concerns about nutrition

Ability to Do Things

To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair? [8]

Completely	Mostly	Moderately	A little	Not at all
☐	☐	☐	☐	☐

How would you rate your fatigue on average? [7]

None	Mild	Moderate	Severe	Very severe
☐	☐	☐	☐	☐

Is someone available to help you if you need it? [10]

Never	Rarely	Sometimes	Usually	Always
☐	☐	☐	☐	☐

Falls[12]

Have you had 2 or more falls in the past 6 months?	☐ Yes
Have you been injured by a fall that required medical attention in the last 6 months?	☐ Yes
Do you feel unsteady when walking?	☐ Yes

See other side to complete

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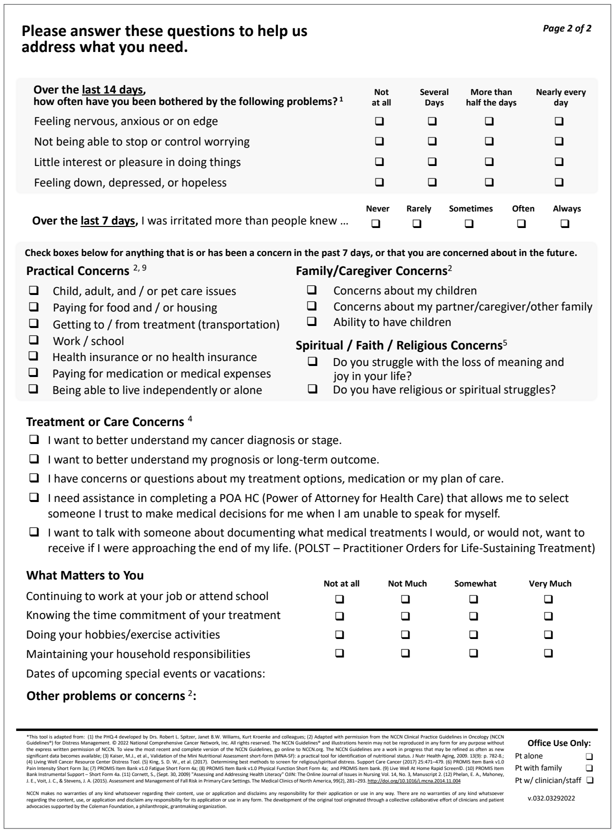

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Please answer these questions to help us address what you need.

Over the last 14 days, how often have you been bothered by the following problems? [1]	**Not at all**	**Several Days**	**More than half the days**	**Nearly every day**
Feeling nervous, anxious or on edge	☐	☐	☐	☐
Not being able to stop or control worrying	☐	☐	☐	☐
Little interest or pleasure in doing things	☐	☐	☐	☐
Feeling down, depressed, or hopeless	☐	☐	☐	☐

	Never	**Rarely**	**Sometimes**	**Often**	**Always**
Over the last 7 days, I was irritated more than people knew …	☐	☐	☐	☐	☐

Check boxes below for anything that is or has been a concern in the past 7 days, or that you are concerned about in the future.

Practical Concerns [2, 9]

- ☐ Child, adult, and / or pet care issues
- ☐ Paying for food and / or housing
- ☐ Getting to / from treatment (transportation)
- ☐ Work / school
- ☐ Health insurance or no health insurance
- ☐ Paying for medication or medical expenses
- ☐ Being able to live independently or alone

Family/Caregiver Concerns[2]

- ☐ Concerns about my children
- ☐ Concerns about my partner/caregiver/other family
- ☐ Ability to have children

Spiritual / Faith / Religious Concerns[5]

- ☐ Do you struggle with the loss of meaning and joy in your life?
- ☐ Do you have religious or spiritual struggles?

Treatment or Care Concerns [4]

- ☐ I want to better understand my cancer diagnosis or stage.
- ☐ I want to better understand my prognosis or long-term outcome.
- ☐ I have concerns or questions about my treatment options, medication or my plan of care.
- ☐ I need assistance in completing a POA HC (Power of Attorney for Health Care) that allows me to select someone I trust to make medical decisions for me when I am unable to speak for myself.
- ☐ I want to talk with someone about documenting what medical treatments I would, or would not, want to receive if I were approaching the end of my life. (POLST – Practitioner Orders for Life-Sustaining Treatment)

What Matters to You	**Not at all**	**Not Much**	**Somewhat**	**Very Much**
Continuing to work at your job or attend school	☐	☐	☐	☐
Knowing the time commitment of your treatment	☐	☐	☐	☐
Doing your hobbies/exercise activities	☐	☐	☐	☐
Maintaining your household responsibilities	☐	☐	☐	☐

Dates of upcoming special events or vacations:

Other problems or concerns [2]**:**

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*This tool is adapted from: (1) the PHQ-4 developed by Drs. Robert L. Spitzer, Janet B.W. Wiliams, Kurt Kroenke and colleagues; (2) Adapted with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management. © 2022 National Comprehensive Cancer Network, Inc. All rights reserved. The NCCN Guidelines® and illustrations herein may not be reproduced in any form for any purpose without the express written permission of NCCN. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org. The NCCN Guidelines are a work in progress that may be refined as often as new significant data becomes available; (3) Kaiser, M.J., et al., Validation of the Mini Nutritional Assessment short-form (MNA-SF): a practical tool for identification of nutritional status. J Nutr Health Aging, 2009. 13(9): p. 782-8.; (4) Living Well Cancer Resource Center Distress Tool. (5) King, S. D. W., et al (2017). Determining best methods to screen for religious/spiritual distress. Support Care Cancer (2017) 25:471–479. (6) PROMIS Item Bank v1.0 Pain Intensity Short Form 3a; (7) PROMIS Item Bank v1.0 Fatigue Short Form 4a; (8) PROMIS Item Bank v1.0 Physical Function Short Form 4a; and PROMIS item bank. (9) Live Well At Home Rapid Screen©. (10) PROMIS Item Bank Instrumental Support – Short Form 4a. (11) Cornett, S., (Sept. 30, 2009) "Assessing and Addressing Health Literacy" OJIN: The Online Journal of Issues in Nursing Vol. 14, No. 3, Manuscript 2. (12) Phelan, E. A., Mahoney, J. E., Voit, J. C., & Stevens, J. A. (2015). Assessment and Management of Fall Risk in Primary Care Settings. The Medical Clinics of North America, 99(2), 281–293. http://doi.org/10.1016/j.mcna.2014.11.004

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Office Use Only:

Pt alone	☐
Pt with family	☐
Pt w/ clinician/staff	☐

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Get tools for The Supportive Oncology Collaborative — Jointly Created Tools And Resources

Supportive Oncology Follow-Up Reference Documents

The SOC created follow-up documents which address the issues identified through patients' answers to the screening questions. This interdisciplinary approach led to a very rich set of resource documents tied to each of the 35 screening questions. These follow-up documents were intended for healthcare providers to use with patients experiencing a concern identified by the screening tool. These documents offer clinicians and other healthcare providers physician-vetted answers to various cancer care questions or concerns, complete with hyperlinks to studies and source documents.

Each follow-up reference document has:

- Process/flow of the next steps to follow if a patient endorses a care concern
- Notes to address unique needs of patient populations
- Web links/handouts for patients to provide further information on the topic
- References and links to professional guidance that support the process/flow of delivering supporting oncology
- Lists of community resources

While practitioners typically have an approach to address each item on the screening tool, their team may have differing approaches. A one-page summary for each item allows standardization and consistency in approaching patient concerns. In addition, the document lists the content for additional information that the provider can share with patients.

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Training Series: Supportive Oncology Care Courses

SOC developed a supportive oncology educational series. The 26 webinar training courses taught oncologists, nurses, physician assistants, social workers, and other health care/oncology professionals who manage patients with cancer to learn more about supportive care. The training courses were grouped into 14 modules reviewed by a National Comprehensive Cancer Network (NCCN) committee and approved for continuing medical education credit (MEC). Initially, they were offered free of charge on the NCCN website. Over 5,500 healthcare professionals completed training (pre-test, 26 courses, post-test) and received credit. Courses continue to be available on the Equal Hope website. Course offerings include:

Communicating Care

- How to Communicate Prognosis
- How to Discuss Practical and Family Concerns with Patients and Families

Supportive Care

- What is Supportive Oncology Care?
- How to Conduct a Supportive Care Screening (Including Distress)
- Documenting Supportive Care Needs and Referrals in a Patient's Medical Record
- The Impact of Distress on Patient Care
- How to Address Patient Distress Utilizing PHQ-4 Results

Symptom Management

- Pain Assessment: The Basics
- Pain Management: Beyond the Basics
- Addressing Symptoms that Impact Quality of Life:
  - Nausea/Vomiting
  - Constipation
  - Dyspnea & Shortness of Breath

Palliative Care

- Primary Palliative Care vs. Specialized Palliative Care
- Reasons to Refer to Hospice and Palliative Care
- Goals of Care
- Advance Care Planning Over Time
- POLST Paradigm — Physician Orders for Life-Sustaining Treatment Paradigm

Survivorship Care

- What is Survivorship?
- How to Conduct a Screening of Patient Concerns and Distress at a Survivorship Appointment
- Comprehensive Care for Cancer Survivors
- Survivorship Factors:
  - Lifestyle and Behavior
  - Common Psychosocial Challenges
  - Common Late and Long-term Effects
- Cancer Survivor Prevention and Screening
- Genetic Testing for Patients, Families, and Survivors

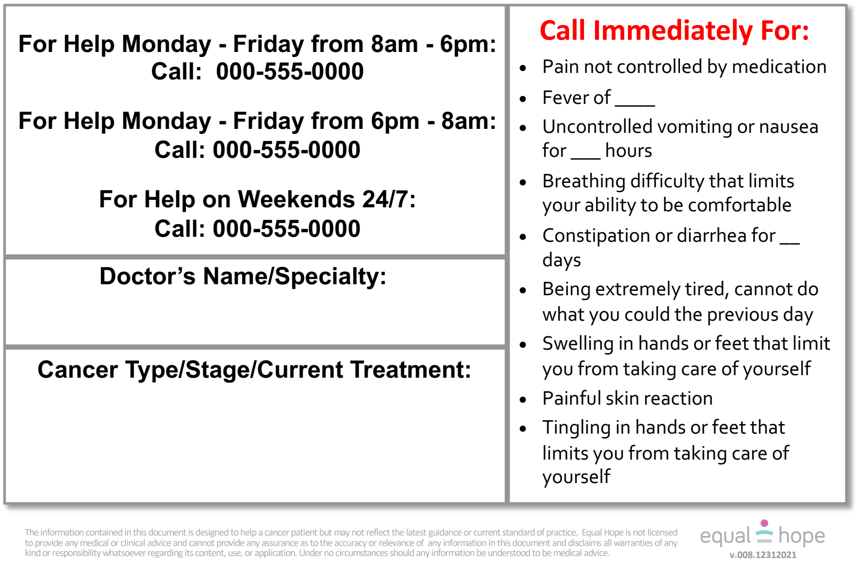
SOC Supportive Oncology Toolkit

The Supportive Oncology Toolkit, first edition, was developed between 2015 and 2019 with input and involvement from over 200 cancer care professionals from Chicagoland institutions and beyond. The Toolkit is a downloadable guide to initiate or enhance supportive oncology care practices for cancer patients. With experience implementing supportive cancer care practices in all types of environments, the Supportive Oncology Toolkit offers cancer care providers nationwide a guide to assess the current state of supportive cancer services. It includes suggestions to improve supportive care practices, the screening tool and resources, the survivorship appointment screening tool, and all the tools created by the Supportive Oncology Collaborative.

Cancer Take Charge Card

Many patients are uncertain of when and if to contact their treatment team with concerns and issues that may arise during their care. To address this dilemma, teams created a "Cancer Take Charge Card" template. This two-sided "business size" card template can be used to customize the contact information of the care team at individual institutions. Providers give the cards to patients and their caregivers so they can easily access their care team.

Cancer Take Charge Card – Example



For Help Monday - Friday from 8am - 6pm:
Call: 000-555-0000

For Help Monday - Friday from 6pm - 8am:
Call: 000-555-0000

For Help on Weekends 24/7:
Call: 000-555-0000

Doctor's Name/Specialty:

Cancer Type/Stage/Current Treatment:

Call Immediately For:

- Pain not controlled by medication
- Fever of ____
- Uncontrolled vomiting or nausea for ___ hours
- Breathing difficulty that limits your ability to be comfortable
- Constipation or diarrhea for __ days
- Being extremely tired, cannot do what you could the previous day
- Swelling in hands or feet that limit you from taking care of yourself
- Painful skin reaction
- Tingling in hands or feet that limits you from taking care of yourself

The information contained in this document is designed to help a cancer patient but may not reflect the latest guidance or current standard of practice. Equal Hope is not licensed to provide any medical or clinical advice and cannot provide any assurance as to the accuracy or relevance of any information in this document and disclaims all warranties of any kind or responsibility whatsoever regarding its content, use, or application. Under no circumstances should any information be understood to be medical advice.

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Survivorship Appointment Screening Tool

The Collaborative survivorship design team developed a tool for patients to complete to provide input to their Survivorship Transition appointment. This tool is a streamlined version of the Supportive Oncology Screening tool; adapted to align with Commission on Cancer, American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) survivorship guidelines and terminology. A section was added to the tool for Lifestyle Factors to align with the ASCO Survivorship Care Plan. The tool is available at no cost in English, Spanish and French.

Reasons to Refer to Palliative Specialty Care and Hospice

The Collaborative design team focused on palliative specialty care and hospice referral and reviewed literature along with existing practices. They documented and piloted “reasons to refer” patients to palliative specialty care from both inpatient and outpatient settings. The team also created “reasons to refer” a patient to hospice care from both inpatient and outpatient settings. They converted their findings to reasons to refer tools and made them available to clinicians.

Best practices dictate that palliative care be introduced early for patients with life-limiting illnesses. The SOC wanted to develop standards for clinicians to reference and help guide when and why to refer patients to palliative or hospice care.

Patient Handouts

After creating tools and resources for use by clinicians and cancer centers, the SOC determined that patients need to understand new processes for supportive oncology being implemented along with cancer care and recommended by national organizations. With that understanding patients would know what they could expect as best practice and how to self manage their care regardless of where they were receiving treatment. Thus, the teams developed patient-facing resources.

Seventy-three patient handouts were created based on various concerns to help empower patients who were seeking self-management support. Organized by care concerns, the handouts provided patients immediate access to physician-vetted information whether they were seeking more information on how to live with metastatic cancer or how to cope with anxiety, including relaxation techniques, psychological treatment (or counseling), and medication.

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Making the Tools and Resources Accessible for All

The Supportive Oncology Collaborative website became a vehicle to amplify the work of the SOC and provide information and access to the tools and resources for care teams throughout participating institutions. The SOC published blogs and academic papers and amplified stories from SOC member clinics to raise the visibility of supportive care services and the professional profiles of the care teams leading the way.

The SOC website became a repository for the publications, a vehicle to publicly disseminate the stories and share the tools, resources, and training modules with cancer care providers. The SOC communications team built a member area of the website that required login credentials to make the resources widely available to SOC members and their institutions. Members could access or download resources at any time. Resource documents contained many links, so they were continually updated. The newest versions were maintained on the website.

The communications team also promoted the SOC tools to cancer providers nationally. Any bonafide cancer care provider could fill in the form to request access for their clinic or institution. The resources drew considerable interest, and over 100 additional cancer centers applied and gained access to all of the tools and resources on the SOC member website.

In 2020, the SOC team reorganized the website to create specific sections dedicated for patient and provider resources. The patient-facing resources were provided as PDF one-pagers that were readily available to cancer patients and their families. Additionally, these documents included physician-vetted answers to commonly asked questions and links to reputable resources.

In 2022, the entire body of work was transferred to Equal Hope, a cancer support organization. The tools, resources, and training webinars are still available on Equal Hope's website today.

Sharing their evidence-based findings with the larger healthcare community

To ensure the work of the Supportive Oncology Collaborative was impactful and could be replicated by healthcare centers around the country, the team put systems in place to gather the necessary data. Each of the tools developed, processes created, or educational modules built and implemented were done with forethought and intentionality.

By putting systems in place, the grantees could collect the necessary data to show evidence of their results.

Those results were compiled and shared not only with their internal teams and within the Collaborative, but with the greater medical community which could greatly benefit from the evidence and information. In addition, this effort allowed practitioners to learn and engage in research and publication, some for the first time.

As a result, team members collaborated in drafting and publishing 60 abstracts/posters/papers in peer-reviewed journals and presented at regional and national conferences and meetings. These included *The Journal of Clinical*

Get tools for The Supportive Oncology Collaborative — Jointly Created Tools And Resources

Oncology, American Society of Clinical Oncology, ASCO Quality, ASCO Survivorship, Association of Oncology Social Work, American College of Surgeons, International Association for the Study of Lung Cancer, National Comprehensive Cancer Network, American Psychosocial Oncology Society, American Academy of Hospice and Palliative Medicine, The Academy of Oncology Nurse & Patient Navigators, and Oncology Nursing Society.

Exposure of the SOC at these meetings gave other professionals methods and approaches to address the needs of their patients. The SOC had over 100 additional cancer programs request access to content and receive it via the website.

> *Developing and presenting abstracts was a huge factor in workforce development for nurses, advanced practice providers, social workers, and physicians and helped to raise the visibility of the initiatives within their institutions.*

Making the Supportive Oncology Collaborative work visible within the institutions contributed to spreading the practices from the Coleman-funded implementation sites to other cancer clinics within participating institutions and beyond.

Get tools for The Supportive Oncology Collaborative — Jointly Created Tools And Resources

7

BUILDING THE FIELD, PROPAGATING SUPPORTIVE CARE PRACTICES ACROSS SITES

Presenting Evidence-Based Practices and Compelling Stories for Widespread Adoption

Supportive oncology doesn't happen in a vacuum. For the impact to benefit all patients, their caregivers, and the healthcare community, it needs to be holistic, have buy-in from various stakeholders, be accessible, and have evidence that it works.

The Supportive Oncology Collaborative (SOC) aimed to ensure that all cancer patients in the Chicagoland area received comprehensive, holistic care by being screened for distress and other concerns and by connecting them with appropriate services or community resources.

To accomplish this, the SOC worked to create replicable care models aligned with the Institute of Medicine (IOM) guidelines, fostering relationships with community cancer support organizations across the region.

The Coleman Foundation initiated the SOC with one cancer clinic per institution and required team members from each site to participate in Cross-Site Working Teams. These teams, focused on specific care concerns, shared their experiences and addressed implementation challenges collectively. The implementation sites included various types of cancer clinics and oncology care centers, enabling teams to learn from each other and iterate on their implementation for improved results.

To amplify the impact of the SOC's work and extend its reach beyond the grantee institutions, The Coleman Foundation enlisted Amdur Spitz & Associates in 2016 as a communication strategist to facilitate and lead the field-building aspect of the SOC's efforts. The communications strategy aimed to inform, engage, and persuade key audiences, convincing stakeholders that providing quality supportive oncology care is feasible and practical.

By deploying both direct and indirect strategies, the communications team effectively engaged various stakeholders, including hospital administrators, policymakers, payers, service providers, funders, and advocates. This strategic communication approach was instrumental in disseminating the practice models and tools across the grantee cancer centers and beyond. The SOC was a catalyst in the movement to improve quality of care and life and reduce costs. These improvements benefit patients, caregivers, and the healthcare community.

The communication efforts during the years covered in this report focused on the supply side — creating more capacity, will, and momentum behind building supportive oncology care practices within provider groups. It did not make sense to build patient demand for services that the providers were still equipping themselves to provide.

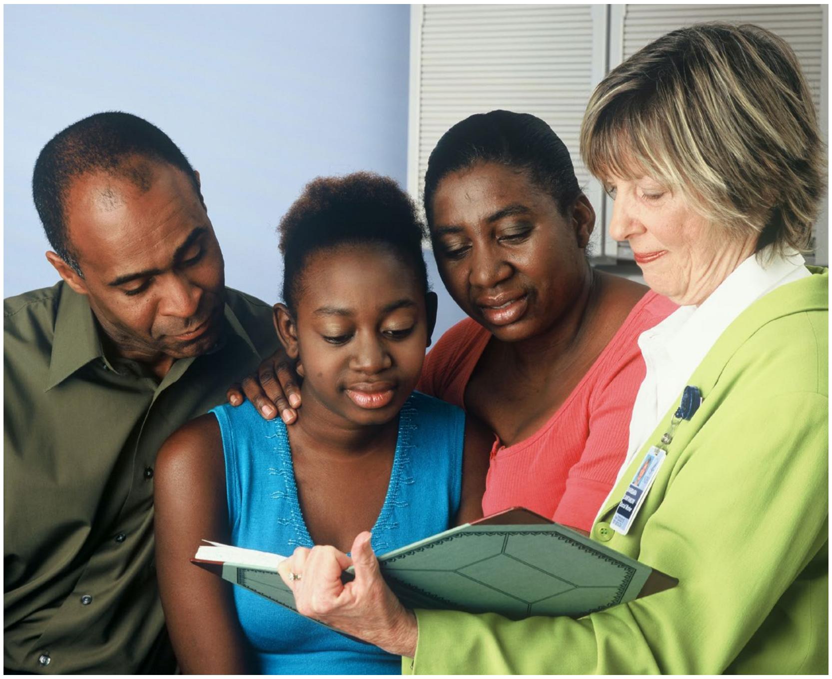
SOC's Strategic Communications Goals

- **Motivate administrators** to support sustainable processes to deliver supportive oncology to all cancer patients
- **Encourage hospital administrations** to grow and sustain supportive oncology programs through additional investments and fundraising
- **Create clinician demand** and drive traffic to tools and resources created by the SOC
- **Profile SOC members'** thought leadership to create more opportunities for them to present publicly and raise their profile within their institutions as representatives of quality supportive oncology care practices
- **Improve collaboration** between the hospital and community providers
- **Demonstrate to payers** the necessity of supportive oncology reimbursement and inform cancer centers about applicable billing codes
- **Convince cancer care sites** to administer distress screenings and referrals for services

Cancer providers needed to demonstrate to their administration the value of providing supportive services for patients' quality of life, quality of care, and/or cost savings overall. They needed to convince them that high-quality services could be provided today and paid for through billing and institutional fundraising. For example, sometimes grantees used funds to hire a social worker or nurse navigator to help connect patients to services. To make the changes sustainable, they needed to make a case to the administration to retain these positions and often expand the roles and staffing levels. But, demonstrating the value was not enough.

THE SOC HAD TO MAKE THE IMPACT VISIBLE.

Just doing the work wasn't going to cut it. The work needed to be amplified and recognized.



The strategic communications team focused on amplifying the work through data and storytelling. Most of the focus was within the industry - or B2B - telling stories to influence the gatekeepers who have decision-making power to sustain, initiate, and spread supportive care practices. These included trustees of grantee institutions, hospital administrators, cancer care providers, clinics, cancer departments within grantee institutions, oncology leaders, payers, and other cancer care institutions nationally.

Starting close to home, the Amdur Spitz team worked with internal communications teams at each grantee site to highlight the work done by the funded clinic and their institution's contribution to the SOC initiative. Patient stories, provider stories, skeptic conversion stories — it was these stories, coupled with the data and evidence, that helped to shine a light on the delivery of supportive care. These stories were published in the hospital and medical centers' marketing materials, newsletters and magazines, websites, and social media channels.

Before long, more and more clinics at each institution regularly provided distress screenings and referred patients to supportive care services. Staff positions, such as nurse navigators and social workers were being added to care teams and paid for by the institution.

Leveraging the work to influence other institutions and making it financially viable and sustainable took a different effort.

Building an Evidence Base

Because anecdotal stories carry little weight in the medical community, part of building the field involved establishing credibility. The SOC did this through publishing 60 papers, posters, and abstracts in peer-reviewed medical journals and presenting them at conferences.

SOC practitioners in the various working teams authored these publications and presented them at national conferences. The prestige of publishing also contributed to their professional development and helped to make them visible as leaders within their institutions. The 60 publications and conference sessions provided evidence of impact and proof of the versatility of success across healthcare institutions.

The prestige of publishing in peer-reviewed journals helped secure buy-in within each healthcare organization. The SOC published articles and abstracts in the following journals: American Society of Clinical Oncology, Association of Oncology Social Work, American College of Surgeons, National Comprehensive Cancer Network, American Psychosocial Oncology Society, American Academy of Hospice and Palliative Medicine, The Academy of Oncology Nurse & Patient Navigators, and Oncology Nursing Society.

Success stories were presented at national conferences and disseminated in hospital and healthcare institution newsletters, through partner institution communication channels, and shared on social media.

ASCO American Society of Clinical Oncology

AOSW ASSOCIATION OF ONCOLOGY SOCIAL WORK

APOS american psychosocial oncology society

ACS AMERICAN COLLEGE OF SURGEONS

Journal of Clinical Oncology®

IASLC INTERNATIONAL ASSOCIATION FOR THE STUDY OF LUNG CANCER

SOCIETY OF BEHAVIORAL MEDICINE

Amplifying Prestigious Presentations and Publications

One method used to amplify the work of the SOC was through a robust and influential Twitter channel. The SOC built up a following that included cancer center leaders, medical journalists, ASCO, NCCN, Livestrong and other cancer organization's official channels, and supportive care thought leaders nationally and internationally. SOC partner institutions and the SOC regularly cross-promoted content on their Twitter channels. The Twitter channel was especially active during conferences when SOC members used it to promote conference sessions and as a communication hub to share ideas. Overall, the Twitter channel was responsible for 12 percent of SOC website traffic during the project's lifetime.

How it was done – Field Building: Strategies

The SOC regularly and consistently engaged gatekeepers, policymakers and decision-makers with persuasive messages to influence the spread of supportive care practices by providing them with feasible, appealing solutions. The IOM report gave the initiative currency because everyone was looking to see how they would be able to check the necessary boxes. The SOC's goal was to get in front of gatekeepers, policymakers, and decision-makers with compelling messages frequently and consistently and offer practical solutions.

The Role of Media

Making the work visible extended outside the conferences and grantee institution channels too. The SOC pursued earned media and secured feature articles in trade publications, such as *Oncology Today*, *Oncology Nursing News*, *Modern Healthcare*, *Hospice News*, *Oncology Business Management*, *OncLive*, *Journal of Clinical Oncology*, and *CURE*.

This allowed the impact of the work to reach clinicians and healthcare providers beyond those who attended national conferences or worked within the institutions where the Collaborative was working. Mainstream news stories in *Crain's*, *WBEZ*, and on *WTTW* further highlighted the significance and achievements of the Chicago area initiative.

Media Features

- Modern Healthcare
- Crain's Chicago Business
- WTTW – Chicago Tonight
- WBEZ Morning Shift

Trade Features

- Oncology Times
- CURE
- Hospice News
- Oncology Business Management
- OncLive from ASCO
- Journal of Clinical Oncology

Partner Feature Stories

- Northwestern
- UI Health
- Rush
- Sinai

Figure 11: Amdur Spitz & Associates Field Building illustration

FIELD BUILDING

Website/SEO
Promote research and practice models, Disseminate tools and resources, platform for training, amplify case studies, profiles and stories

Social Media
Build thought leadership profiles of consortium members, create Data illustrations, info-graphics, social memes, charts, quotes and testimonials

Conferences & Publications
Publish impact data and present at professional conferences. Amplify publications through trade media. Use uniform graphics and branding

Media Relations
Generate media coverage of about supportive oncology collaborative, case studies, research and impact stories from collaborative

Influencer and stakeholder communication
Collaborate to tell Supportive Oncology stories through internal and external member communications vehicles to leverage institutional support for SO

Interactive Website: The Main Hub

The Supportive Oncology Collaborative website served as an information hub for the wide array of organizational and individual SOC members. It promoted events, gatherings, published articles about members and successes, and served as a repository for all of the publications. The SOC website also housed all of the tools and resources created by the SOC in a members-only area of the website. Cancer care providers outside the collaborative could apply for access, which was granted to 100 additional facilities. More than 500 registered members downloaded those screening tools 1,275 times. Most cancer centers downloaded them to their internal office drives for daily use.

In 2021, the SOC created patient-facing handouts for self-managed care. The communications team created a patient portal to house these resources in an easily navigable interface. The website became a vehicle for cancer patients everywhere to access self-managing resources.

The SOC published a quarterly member e-newsletter. This newsletter included news from member sites, publications, conferences, notifications of updates to resource materials on the website, training opportunities, and notices of updates or changes to billing codes and reimbursement policies.

In addition, in 2020, the SOC created a toolkit. The toolkit is a comprehensive set of materials that introduce care teams to supportive oncology care principles, and provides a step-by-step guide to replicate the delivery of supportive oncology to implement the screening tools and resources in clinical and community practice settings.

Making it Easier to Begin: The SOC toolkit provides replication instructions, tools, and resources

Few oncology professionals would dispute that providing supportive oncology care to their patients is the right thing to do. The biggest barrier is how. The Supportive Oncology Toolkit provides instructions for building a supportive care network like Chicago's in other communities, helpful billing and payer information, tools, and resources.

Field building highlights

160

qualified cancer centers nationally requested and received the SOC Toolkit and Resources

100

cancer institutions requested and were granted access to download tools and resources from the member-only website

60

publications in peer-reviewed journals and 60 conference presentations

1,275

downloads of Supportive Oncology screening tools

5500+

healthcare professionals completed training (pre-test, 26 courses, post-test) on the NCCN website and received continuing medical education credit.

12%

of SOC web traffic came from the Professional network on Twitter

500+

clinicians registered to the website. An average of 19 unique users logged in each day. Users spent an average of 4 minutes each session.

Growing Momentum

These communications-focused approaches made the Supportive Oncology Collaborative's significant work more visible and tangible. It allowed more people to take notice and consider implementing supportive care practices at their cancer centers, and helped elevate SOC participants' careers.

Just as importantly, through evidence-based practice, healthcare providers have improved the care they deliver to their patients. Perhaps unsurprisingly, each location that implemented the work of the Supportive Oncology Collaborative saw positive results.

A contributing factor to these positive results was another Coleman-funded initiative, which aligned with its cancer program. Depending on the hospital's cancer registry, up to 70 percent of patients with a serious illness may have a cancer diagnosis. Due to this high percentage, the Foundation began exploring palliative care and learned about the shortage of palliative care doctors. Thus, the Foundation worked with a collective of providers to create a training program to deliver palliative care to more patients.

The Coleman Palliative Medicine Training Program committed to workforce development

Over ten years ago, The Coleman Foundation began funding a training program created to address the shortage of palliative care providers. The program, which continues today, provides comprehensive training that enhances clinical management and communication skills to care for patients with complex, advanced illnesses. The training also aims to build the interdisciplinary workforce in palliative and supportive care, increase access to supportive care, and improve quality of care.

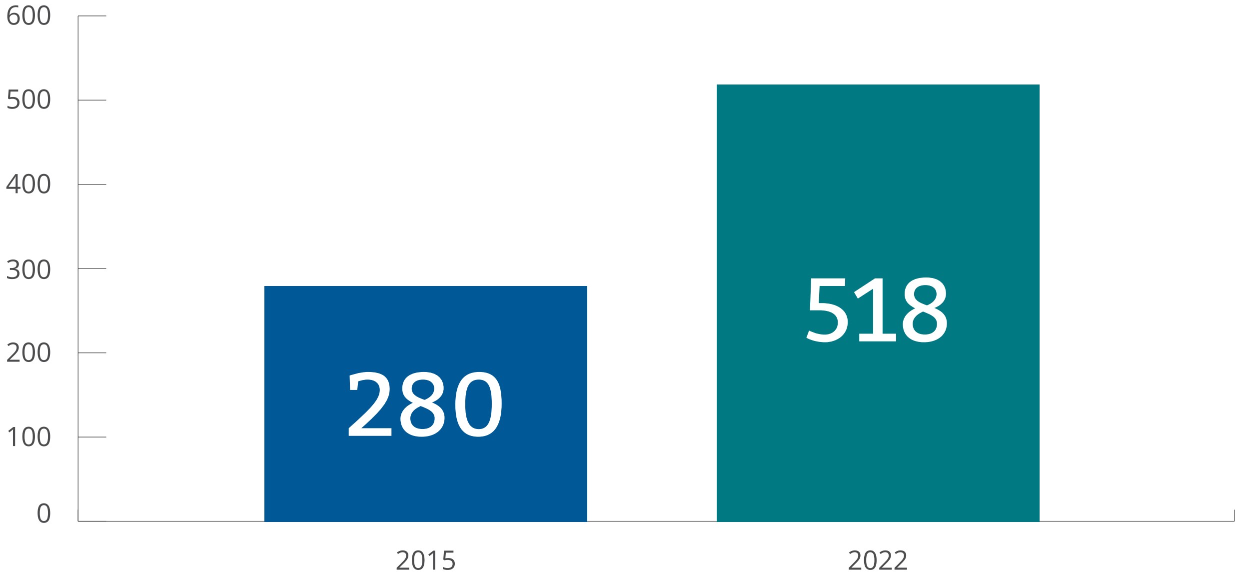
There is some overlap between workforce development efforts of the Supportive Oncology Collaborative and Palliative Medicine Training Program.

Both initiatives contribute to an intentional effort to grow and improve training of oncology providers to deliver supportive care. National cancer organizations recommend starting primary palliative care at the time of diagnosis of a serious illness to assist patients with pain management, symptom management, stress, and anxiety, and continue care through survivorship and end of life. Components of supportive oncology are crucial to quality cancer care as illustrated in the "Cancer Care Continuum," presented by Dr. Patricia Ganz at the 2014 ASCO Annual Meeting.

In 2015, Stacie Levine, MD, FAAHPM, Co-director of the Coleman Palliative Medicine Training Program, and Chief of Geriatrics and Palliative Medicine at the University of Chicago Medical Center stated, "My biggest concern is the workforce shortage. There were only 280 funded Hospice and Palliative Medicine Physician Fellowship Training positions in the whole country."

Today, eight years later, that number is 518.

Figure 12: Funded Hospice and Palliative Medicine Physician Fellowship Training Postitions in the USA



8

SUCCESS FACTORS & ACCOMPLISHMENTS

Impacts recognized by individual sites and more broadly

Changing how institutions run their practices isn't easy, but the Supportive Oncology Collaborative (SOC) achieved remarkable results because of the willingness of its members to come together and dedicate their time and resources to better meet the needs of their patients and their respective support teams.

The impact of their work cannot be underestimated. While this list isn't exhaustive, it does represent how much can be done when parties come together with skillful project management and one goal in mind.

- The number of cancer patients screened for supportive care concerns increased from 17% at the beginning of the initiative to over 85% by the end of 2021.
- Over 60,000 cancer patients at grantee institutions in Chicago were screened using the SOC tool to address distress and a wide range of care concerns.
- Participating Coleman grantee cancer centers had nine social workers, which increased to 25 during the program period based on the proven patient needs for social work services during the SOC project.

Other factors that reflect the SOC's success:

- Hospital administrations sustained the program through fundraising efforts, payer reimbursement, and/or internal funding and budgets. Sites continue offering supportive oncology services to their target patient population and other cancer patients past the end of the grant period.
- Payers work with providers to improve reimbursement for supportive oncology services. Changing reimbursement takes effort; success can be measured by changes in payer coverage policy and/or pending plans to adjust payer policy.
- National thought leaders connected to the Supportive Oncology Collaborative by sharing results, tools, methods, successes and challenges.

EMBRACING THE WHOLE PERSON, MIND, BODY, AND SPIRIT

- Increased visibility of the Collaborative in the medical community through abstracts and posters presented at cancer conferences.
- Expanded impact of the Collaborative through submission of papers that incorporated lessons learned.

There are many reasons why the Collaborative's work has been a success and it's in no small part due to the dedication, commitment and support of several organizations, working groups, and communications teams.

Key elements of this successful collaboration:

1. It was research-driven and inquiry-based. Rather than asking practitioners to apply a prescribed method, Coleman empowered providers by engaging them to work together to identify and solve challenges.
2. It was inclusive, interdisciplinary, and non-hierarchical. Participants focused on how they could deliver the care their patients needed, regardless of their clinical job title.

3. It hired professional facilitators with content expertise in building business models in healthcare to facilitate collaboration, structure work groups, and provide administrative support.

4. It was structured for personal and professional success. Through a communications initiative and publishing in peer-reviewed journals, the Supportive Oncology Collaborative created pathways for engaged professionals to be visible and recognized. Amplifying their stories helped practices spread from a handful of clinics to entire institutions, which have since bought into the value proposition and are now investing in staff to make services sustainable.

5. It worked with business structures, not against them. Making sustainable change means the benefits of providing supportive cancer care must make economic sense for the institution. From the onset, the Supportive Oncology Collaborative made concerted efforts to work with payers and health systems to demonstrate:
   - improved care helps contain cost
   - value across many matrices in which healthcare institutions are evaluated
   - many services can be reimbursed if the provider looks outside its silo

Evidence-based outcomes

Starting with just a couple of cancer clinics at each facility, the Supportive Oncology Collaborative demonstrated its impact and spread the work across the institutions. It improved the quality of life for patients and their families affected by cancer from cancer diagnosis to cancer survivorship and end-of-life.

Over the last several years, clinicians participated in design and cross-site working teams to create and establish methods to improve the delivery process of supportive oncology care, including numerous tools and resources.

Participating hospitals used the distress screening tool to screen over 60,000 patients and made referrals to internal and community cancer resources.

In addition, over 100 institutions nationwide have requested and received free access to the various tools, resources, follow-up documents and clinician training courses shared through the website. Furthermore, clinicians have participated in joint efforts to publish findings of their work, which resulted in 60 national publications.

Reimbursement Facilitation

In the early stages of the development of the Supportive Oncology Collaborative, the reimbursement team conducted an exploration and discovered that many billing codes for supportive oncology existed in the master file. However, since hospitals were not providing supportive oncology, staff were unaware that the billing codes existed and were not using them to code for reimbursement for services.

This is a key challenge to delivering supportive oncology since reimbursement and funding of these services is vital for sustainability and ensuring the services continue to be offered.

Attaining reimbursement for comprehensive supportive oncology could not be done by specific medical institutions or trade organizations, due to contractual relationships and other factors. It took the SOC reimbursement team plus the SOC design and process improvement teams to understand what reimbursement methods were being used and where there were gaps.

In addition, the reimbursement team collected data and metrics on quality and performance of supportive oncology services. The information supported discussions about reimbursement with payers and health system leaders. The objectives of the reimbursement facilitation were to:

- Identify current coverage by service and gaps in coverage
- Engage payers willing to assess and identify ways to support reimbursement in various payment forms, such as fee-for-service, bundled payments, and Accountable Care Organizations (ACOs)
- Engage health system/provider administrators, as emerging “payers” in ACO’s, bundled payment, and large system settings
- Develop a case for reimbursement for supportive oncology-based medical need utilizing data collected

The reimbursement efforts were spearheaded and led by The Center for Business Models in Healthcare.

The Initiative's Outcomes

The SOC's outcomes were robust and important, for both patients and their healthcare providers. As a result of the working groups and care teams, outcomes include:

- Collaboration by multiple service providers having competencies in cancer care to work together and share knowledge, skills and resources for supportive oncology practices.
- Development of process design and execution approaches for implementation, including engagement of community service providers.
- Collaboration between hospitals and community service providers to extend the delivery of psychosocial support.
- Hospitals support a process that screens for distress and makes services available or collaborates with community providers to provide services.
- Six major medical centers in Chicago have internally consistent organizational definitions and visions of supportive oncology, which include: distress, psycho-social care, palliative care, survivorship care and effective hospice referral, with supportive oncology services starting at diagnosis and continuing through survival and end-of-life.
- Improved supportive oncology processes across ten or more medical facilities for distress/psychosocial care, palliative care, survivorship care, and hospice care for a large number of cancer patients.
- Workforce development to improve understanding of supportive oncology guidelines and best practices for physicians, mid-level providers, and staff that work with cancer patients across participating organizations.

> *"Through collaborating, I felt better equipped to have conversations with patients and families and support them because I had access to the information we created together. This has had a positive effect on disseminating information to all of our patients and families but especially to those who are often marginalized in the healthcare system."*
>
> — University of Chicago

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THE COLEMAN FOUNDATION SETS THE STAGE FOR CONTINUING DELIVERY OF SUPPORTIVE CARE

The Coleman Foundation Spearheads Persistent Supportive Care Efforts

For decades, The Coleman Foundation has funded cancer programs to improve quality of life for cancer patients and survivors in the Chicagoland area, and the Foundation conducted an exploration of supportive oncology services. Research has shown that early access to supportive care may help patients take preventative measures to avoid or reduce the severity of side effects or complications that may interfere with or delay their treatment.

Supportive oncology focuses on improving the quality of life for patients and their families affected by cancer from diagnosis to survivorship and end-of-life. The goal of supportive oncology is to reduce the physical and emotional burden from an illness through psychosocial support, pain and symptom management, and integration of complementary therapies.

In 2013, this exploration sought input from leadership and supportive oncology professionals from over 35 organizations, including 13 cancer treatment sites, 14 cancer support centers, and eight hospice organizations. With deep concern for equity in access to supportive care, The Coleman Foundation included institutions that served patients across the healthcare spectrum, from safety net and community hospitals to academic medical centers. Every step of the way, the SOC designed tools, practice models, and resources that could be implemented with quality anywhere patients accessed care.

While most cancer care providers had implemented or started implementation of some aspects of supportive oncology, at the time, none in the Chicagoland area had achieved the level of quality and service delivery demanded by the Institute of Medicine's 2013 Report "Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis". Providers found it challenging to implement effective changes in supportive oncology that address recommendations and requirements while adapting to local/regional healthcare guidelines, resources, and patient needs.

BUILDING A NETWORK OF SUPPORT FOR HEALTHCARE PROFESSIONALS AND EQUIPPING THEM TO DELIVER EXCEPTIONAL CANCER CARE

IN JUNE 2014,

The Coleman Foundation launched the Supportive Oncology Collaborative and awarded grants to several institutions to improve their processes in delivering services and expand to other sites.

Over the past seven years, The Coleman Foundation invested nearly $8 million towards the collaboratives for adult, pediatric, adolescent, and young adult (AYA) supportive oncology programs at 17 institutions. The impact of this work has been remarkable and far-reaching.

The Collaborative assessed and delivered psycho-social support to cancer patients and their families from diagnosis throughout their lifespan. It also sought to educate providers, patients, and payers about the benefits of psychosocial services, as well as share findings and tools with healthcare professionals and the broader cancer care community.

Over the last several years, participating hospitals have screened over 60,000 patients for distress/care concerns and made referrals to community cancer resources. Clinicians have participated in joint efforts to publish the findings of their work, which resulted in over 60 abstracts with a national focus. The working teams created 73 patient self-management tools with resources for various patient care concerns.

In addition, over 100 institutions nationwide requested and received free access to the SOC's tools, clinician trainings, resources, and follow-up patient documents through the Collaborative's website.

Today, a significant number of cancer patients in the Chicagoland area are screened for supportive care needs and provided with access to resources. Although The Coleman Foundation's funding of the Supportive Oncology Collaborative has not changed the trajectory of cancer for all patients, the organization is pleased that its support has made living with cancer less stressful and more manageable for thousands of patients and their families.

The work begun by the Supportive Oncology Collaborative was just the starting point. The impact goes far beyond patients, their families, and providers. For example, the work influenced change and adoption across cancer care organizations, such as:

- The SOC developed a survivorship screening tool "Questions for your survivorship appointment", which is the basis for a screening tool that ASCO's survivorship committee is currently testing and incorporating into the next version of their survivorship guidelines. The ASCO survivorship team is using the SOC model to guide how they are aligning guidelines.
- The Association of Community Cancer Centers conducted a membership survey of supportive care services offered by their members, including how the services are paid for. This survey was designed and led by SOC participating leaders Al B. Benson III, MD, and Sheetal Kircher, MD, utilizing their experience from working within the Collaborative. The results were published in the *Journal of the National Comprehensive Cancer Network* (JNCCN).

Taking the Supportive Oncology Collaborative's Work into the Future

After several years of The Coleman Foundation support for the Supportive Oncology Collaborative, the Foundation realized the enormous impact the Collaborative made on clinicians, hospital administrators, and cancer patients and their caregivers. The Coleman Foundation sought the Collaborative's accomplishments to flourish beyond its funding and thus asked their grantee partner Equal Hope to steward the tools and resources created through collaborative endeavors. From the very beginning of the SOC, Equal Hope was an influential partner within the Collaborative's convenings and discussions.

Subsequently, the Foundation assigned all SOC resources to Equal Hope, a long-standing partner whose mission and focus is on eliminating cancer disparities in Illinois. As a non-profit that advocates for equity in access to high-quality cancer prevention and care, Equal Hope will continue to shepherd the SOC's work and make its resources broadly accessible to cancer care providers, patients, and caregivers. These resources are housed within Equal Hope's website, where it provides information and tools regarding cancer education, screening tools, treatments, self-care, and community resources. As the steward, Equal Hope is currently working to expand public utilization by translating key resources into Spanish and creating literacy level appropriate tools to compliment the site. Equal Hope also disseminates these resources widely through on-the-ground outreach and programming, social media, and radio broadcasting.

The Coleman Foundation continues its commitment to programs and services that promote supportive oncology. Starting in 2022, the next generation of Coleman's investments in supportive oncology places a particular emphasis on reducing cancer disparities among communities of high need in the Chicago metropolitan area. In the continuation of its support, Coleman has invested in both new and former grantee partners. From 2022 to present day, Coleman made nearly 40 grants in supportive oncology totaling over $1.5 million.

How stakeholders can commit and carry supportive oncology into the future?

While much has been done, there is still work to do in the future to provide high-quality supportive oncology care for all cancer patients and their families. The following are recommendations for each set of stakeholders.

Administrators of Cancer Center Programs

For cancer care to be comprehensive and address patients with challenging social determinants of health, supportive oncology care services are vital. Administrators should review the resources available at their cancer program. A recent paper provides an in-depth analysis of what comprehensive care services are needed at all cancer programs. This paper also provides potential reimbursement codes in the appendix (Table A1).

There are reimbursement codes available for some of these services; however, many cancer centers do not have them available on their billing master list of codes to use. Cancer centers can review their billing charge master to ensure reimbursement codes are available to their team and evaluate and share how to bill for these codes when appropriate and relevant.

Organizations, such as The Association for Community Cancer Centers and the American Society of Clinical Oncology, continue to advocate for reimbursement of these services. Cancer centers are advised to follow these organizations to find additional opportunities for their programs.

Community Cancer Care Providers

Cancer centers should know what resources are available in their surrounding communities and what trusted information can be shared with patients to help them access supportive care. The Equal Hope patient self-management tools include weblinks and phone numbers to local resources where relevant.

There is also a Google map of cancer support resource centers in northern and central Illinois available at: http://cancer-help.me/communitycancerresourcecenters. Cancer centers can share these resources with their team and with their patients.

Philanthropic Supporters

While there has been some improvement in reimbursement and availability of supportive care services, there is still a lack of resources to address the most common needs of patients with cancer and their families. Access to transportation, healthy foods, nutrition services, and the ability to address co-pays not covered by assistance programs continue to be near the top of the list, among many others. Oftentimes, cancer patients and their families need assistance in accessing social services and understanding how they qualify for support. These are areas of need that philanthropy can help fulfill.

The Coleman Foundation Looking Ahead

The next generation of Coleman's investments in cancer includes strategies in both prevention and supportive oncology. These investments will be aligned with Coleman's current strategic plan, which has an overarching goal of increasing equitable health outcomes so that there is a higher quality of life among the underserved and under-resourced. In pursuit of this goal, Coleman established a learning agenda that focuses on access to care, workforce development, and chronic disease prevention and management through a lens of cultural competence and patient-centered care. More specifically, Coleman aims to learn about the barriers to healthcare among vulnerable populations, as well as ways to educate and train various healthcare providers (e.g., nurses, community health workers) to meet the changing needs of the field and their diverse communities. Additionally, Coleman has been supporting and will continue to invest in efforts that increase outreach, education, health literacy, and screenings to help prevent chronic illnesses and empower communities to better manage their health and make informed decisions.

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