

# Cancer: Taking Care of the Mind and the Body



A Series by *Real World Health Care*  
**2018**

Cancer patients untreated for behavioral health conditions may not make sound medical decisions, may avoid helpful treatments, or may not adhere to medication or other therapies, notably worsening health outcomes. If left untreated, behavioral health disorders among cancer patients have been shown to negatively influence the underlying cellular and molecular processes that facilitate the progression of cancer.

***Cancer: Taking Care of the Mind and the Body*** is a recently published series of articles that spotlights the organizations and efforts dedicated to making sure that those with cancer are getting the behavioral health treatments they need. Please accept this complimentary copy as our way of thanking you for your commitment to helping these patients and advocating for healthier futures.

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## A Message from Our Sponsor

As the founding sponsor of Real World Health Care, the HealthWell Foundation is committed to helping patients get the medical treatments they need, regardless of their ability to pay. We've seen first-hand how financial distress can impact the health and lives of individuals and families. Cancer patients with behavioral health conditions are particularly hard hit; according to the American Society of Clinical Oncology (ASCO), patients with some forms of cancer incur \$8,000 more per year in health care costs than cancer patients without behavioral health conditions.

In keeping with our mission, we are now accepting applications for our Cancer-Related Behavioral Health (CRBH) Fund, specifically for treatment-related behavioral health issues in cancer. The Fund provides financial assistance to individuals with a diagnosis of cancer to help with cost-shares (deductibles, coinsurances and copayments) for covered services rendered by behavioral health providers (psychiatrists, psychologists, clinical counselors, and licensed social workers).

We invite readers of Real World Health Care to learn more about our CBRH Fund and how you can support it by visiting [www.HealthWellFoundation.org](http://www.HealthWellFoundation.org).

# Can Psychosocial Care Increase the Value of Cancer Care?

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This week, Real World Health Care interviews [Suzanne M. Miller](#), PhD, Professor of Cancer Prevention and Control and Director of Patient Empowerment and Health Decision Making at [Fox Chase Cancer Center](#) (FCCC). Dr. Miller is on the Board of Directors of the [HealthWell Foundation](#) and the [Society of Behavioral Medicine](#) (SBM), and serves as Chair of the Board of Directors of the [New Jersey Health Care Quality Institute](#). She also serves as Editor-in-Chief for SBM's flagship journal [Translational Behavioral Medicine: Practice, Policy and Research](#).

At FCCC, Dr. Miller's work focuses on developing, evaluating and implementing psychosocial interventions that can be readily integrated in ongoing cancer care to improve outcomes for patients and their families, especially those outcomes related to patient-centered experiences of their cancer diagnosis. FCCC's goal is to integrate understanding of the psychological response and negative psychological consequences of a cancer diagnosis with a broader medical management of the patient, and thereby achieve optimal patient-reported outcomes.

We discussed the work of SBM and explored the link between cancer and behavioral health. We also talked about behavioral health screening and the importance of integrated care.

## Advocating for Psychosocial Care

**Real World Health Care:** How does the Society for Behavioral Medicine address the issue of psychosocial care for cancer patients?

**Suzanne Miller:** SBM advocates for NIH research funding so members and others working in cancer have the dollars they need to discover and scale new behavioral treatments and care approaches. SBM also shares the latest cancer care research with members through our journals and [annual scientific conference](#). This gives them the best information for planning new studies and for helping patients in their clinics.

Our flagship journal, [Translational Behavioral Medicine](#), publishes studies showing how successful behavioral treatments can move from the lab to the clinic where they can help real patients. The journal's [February 2018 issue](#) highlights the use of [genomic information in cancer care](#) and in screening cancer patients' family members.

Other papers published in 2017 feature best practices for encouraging more [colon cancer screening](#) and for helping [breast cancer patients](#) cope with diagnosis and

survival. This recent research by Allicock, et.al. (2017) investigated the drivers of successful implementation of a peer-support program in rural cancer patient populations. It identified possible barriers to the effectiveness of similar community-engaged programs in improving survivorship outcomes.

Several SBM members are at the forefront of successfully training providers to deliver existing empirically supported interventions to patients as well as shifting interventions to user-driven, mobile-friendly, web-based platforms to widen reach in treating anxiety and depressive disorders in cancer patients.



Dr. Suzanne Miller, Fox Chase Cancer Center

## Link Between Cancer and Behavioral Health

**RWHC:** What are some of the most common behavioral health problems associated with having cancer?

**SM:** A cancer diagnosis brings a wealth of psychological challenges. In fact, adults living with cancer have a six-time higher risk for psychological disability than those not living with cancer. Patients and families have to deal with not only the physical stress to their lives and potential livelihoods, but also with family dynamics and changes in their sense of self and future.

Cancer patients also must make numerous decisions while they are in an extremely emotional state. They must decide what treatments to pursue, both initially and over the long term, how to cope with treatment side effects, how to deal with disability and maintain an independent identity, and how to maintain quality of life.

Depression and anxiety are common diagnoses associated with these challenges, yet, despite all of this, social or emotional support is offered in less than half of cancer patients' care. If cancer patients have certain behavioral health conditions and they are not treated for them, it can negatively impact health outcomes by affecting their ability to make sound medical decisions, by decreasing the chances of them seeking and adhering to treatment, and by affecting their immune systems and ability to fight off cancer. Behavioral health issues can also contribute to harmful health behaviors such as smoking. Adults with depression are more likely to smoke heavily and less likely to quit smoking. Smoking is not only linked to cancer incidence but is also associated with

a higher burden of side effects reported by cancer patients during treatment and in survivorship.

**RWHC:** Can behavioral health problems exacerbate physical or biological problems in cancer patients?

**SM:** Yes, in a number of ways. They interfere with rational decision-making about one's treatment and one's life choices. They also undermine adherence to needed regimes, especially over time. For example, after a breast cancer diagnosis, most patients undergo recommended surgery. However, following surgery, many patients are advised to go on hormonal regimes that can be toxic and difficult to endure. Depression and anxiety can undermine adherence to those regimens.

At a physiological level, healing can be delayed or impaired, making patients less likely to reenter society and more likely to experience relapse and recurrences. For example, cellular and molecular processes can be negatively influenced by untreated behavioral disorders in cancer patients, which can lead to the cancer's progression. Importantly, this connection can also work conversely, meaning psychological treatment has been found to improve underlying biological status. A compelling example of this was shown by Thornton, et.al., (2009) who used a psychological intervention to alleviate symptoms of depression among cancer patients and reduce the presence of inflammatory markers found in the body. This is important because inflammatory markers are an indicator of the stress that is being placed on a person's immune system. Since mental health issues are also associated with smoking and other unhealthy behaviors, behavioral health problems appear to contribute to worse health outcomes for cancer patients and survivors.

## Attention and Support

**RWHC:** Do you think behavioral health impacts of having cancer get enough attention from the provider community?

**SM:** The provider community is well aware of and sympathetic to the kinds of challenges patients face. However, they often lack the time and expertise needed to sufficiently screen for depression and anxiety and related psychological issues. This serves as a barrier for provider compliance with recommendations that patients with behavioral health problems receive evidence-based psychological treatment. Further, there is a lack of available costs and infrastructure to pay for appropriate psychosocial interventions. All of this amounts to only 14% of cancer patients receiving behavioral health counseling. Therefore, we are faced with behavioral health issues like depression, which is common in cancer patients and is known to negatively influence cancer outcomes, which are not being addressed sufficiently in the current standard of care.

**RWHC:** Are there any stigmas attached to this from the patient's perspective?

**SM:** Cancer has been the big “C” from the time people became aware of it. More than any other disease, patients fear it and suffer tremendous concerns about the social impact for them and their families when people learn that they have a cancer diagnosis. Further, cancer doesn't go away. Survivorship and late effects last well after the initial diagnosis, even for early stage cancers. In fact, for a third of cancer patients, distress persists more than a year after their cancer diagnosis and comes in the forms of worrying about the future, feeling lonely or isolated, and financial concerns—to name a few. In addition, there is a very real insurance threat to the individual from having a so-called “pre-existing” condition such as cancer.

**RWHC:** Who are the best people to advocate for a cancer patient's behavioral health? What happens when a patient doesn't have a strong support network?

**SM:** I believe a well-coordinated health care team, combined with patient and community resources, is the best way to advocate for behavioral health. Each one brings a particular expertise that can speak not only to the public, but also to policy makers. At the patient level, patients need strong support from their families, peers, work, and their health care providers. Among the health care team, mental health providers are especially well-equipped to advocate for patients' behavioral health needs. At the broader level, the system must consider psychosocial intervention as integral to patient care as a medical intervention. In fact, the two are synergistic, and we must be bold in the serving of the relevance of behavioral health in the overall health of patients diagnosed with cancer.

## **Behavioral Health Screening**

**RWHC:** What sort of challenges need to be overcome to make a case for the value of psychosocial care for cancer patients?

**SM:** It is extremely important to show the viability of screening for cancer distress in a cost-effective manner, especially when using information technology (IT) that can help relieve the burden on the health care system. That is exactly why the National Cancer Institute is looking to fund projects that use IT to support the systematic screening and treatment of depression in cancer patients. In addition, it's very important to show the value of psychosocial care in terms of its impact not only on psychosocial outcomes like depression and anxiety, but also on improving adherence, reducing readmission rates, improving survival rates, and reducing recurrence rates.

Value is defined as health outcomes achieved per dollar spent, so if psychosocial care can improve adherence and survival rates while also decreasing readmission and



recurrence, then it can certainly be argued that psychosocial care will increase the value of health care provided.

## **The Whole Patient**

**RWHC:** How can improving the integration of care and caring for the “whole patient” help to improve behavioral health among cancer patients?

**SM:** Cancer patients face reality-based anxiety and depression, stigma, changes in self and family identity, and a more frightening and uncertain world. When the health care system limits care to medical interventions, it not only makes the impact of those interventions less effective, but it also fails to recognize the impact of psychosocial influences on cancer prognosis and survivorship.

While some patients may find their way in psychological or social support interventions, if these interventions are not well-integrated within the context of the medical care model, they limit their impact and their validation. This means that patients will be much less likely to have access to, and to uptake, critical psychological resources that can not only improve quality of life, but the quantity of life as well. An integration of care ensures that patients get access to these resources and that no patients are lost to follow-up when it comes to behavioral health care. It provides the patient with a team of support that tackles the physical, social, and emotional challenges that come with a cancer diagnosis.

# How to Get Over It: Fear of Vomiting

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*By Ken Goodman, LCSW, Anxiety and OCD Treatment of the Valley and Clinical Fellow, Anxiety and Depression Association of America*

This week, Real World Health Care provides information on the fear of vomit by sharing an article originally published by the [Anxiety and Depression Association of America](#). We encourage you to [visit the ADAA blog](#) to read or take part in the lively commentary discussion that follows the original post for additional insights.

*Editor's Note: Nausea and vomiting are two common side-effects of chemotherapy. Even if cancer patients don't experience these side-effects as part of their treatment, the threat looms large, which can have a significant impact on one's quality of life.*

If you have a fear of vomiting, just reading the title of this article might make you a bit queasy. The mere mention of the “V word” might send you into a state of anxiety. If you can relate, I encourage you to press on despite your worry, so you can take the first steps to overcoming it.

## Emetophobia?

No one enjoys vomiting and everyone thinks it's disgusting, but most people are not afraid of it. But if you suffer with this type of phobia (specifically known as emetophobia), you are not only repulsed by the idea of vomiting, you fear it. Many people say that the anticipation of vomiting is often worse than the act itself.

And because you don't know when it will happen, you are constantly on guard, rearranging your life to ward off any possibility of puking.

## What Causes Nausea?

Stomach discomfort and nausea can be caused by motion sickness, a stomach bug, food poisoning, excessive eating or drinking, food intolerance and...anxiety!

That's right. Anxiety and worry can cause stomach discomfort and nausea. And if you don't vomit when you're anxious...you won't!

## Treatment Works

Treating vomit phobia is best accomplished through cognitive-behavioral therapy (CBT) and exposure and response prevention (ERP). Treatment involves correcting faulty beliefs, reducing avoidance, and confronting challenging situations step-by-step. You



Ken Goodman, LCSW,  
Clinical Fellow, Anxiety  
and Depression  
Association of America

are given tools, a new perspective, a winning mindset, and a strategy for facing your fears. Your motivation for ending your suffering is important because the therapy does take time, hard work, and courage. You must have self-discipline and determination to win. And if you do...you can beat emetophobia!

[Learn more about vomit phobia.](#)

**Ken Goodman**, LCSW, practices individual and group therapy in Los Angeles to help anxiety and OCD sufferers free themselves from debilitating fear. He is the producer of *The Anxiety Solution Series: Your Guide to Overcoming Panic, Worry, Compulsions and Fear*, a step-by-step self-help audio program. [Visit his website.](#)

**Now available – Ken Goodman hosts an ADAA webinar on “Overcoming the Fear of Vomiting.”** [Watch the video on ADAA’s YouTube channel.](#)

# Cancer Affects More Than the Body

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*By Hildy Dillon, Vice President, Education and Support Programs, Cancer Support Community*

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC), including its Gilda's Club affiliates, is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of nearly 50 local CSCs and Gilda's Clubs with 120 satellite locations that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research & Training Institute conducts cutting-edge psychosocial, behavioral and survivorship research.

This article is excerpted from CSC's *Frankly Speaking about Cancer: Treatments & Side Effects*, which can be downloaded from CSC's website.



Hildy Dillon, Vice President, Education and Support Programs, Cancer Support Community

## **Talk to Your Doctor**

Cancer not only affects your body, but it also has an impact on your thoughts, feelings, beliefs and attitudes. If you or your loved ones have received a cancer diagnosis, know there are actions you and your health care team can take to improve your emotional wellbeing during this experience. Emotional distress is very common. Professional help is advised if depression or anxiety is affecting you; do not be hesitant to obtain expert assistance.

## **Emotional Distress**

Finding out you have cancer can be very challenging. Allow yourself time to adjust to the news. The emotional impact of a cancer diagnosis on an individual or family can vary greatly.

There may be shifts in different aspects of your life, including issues related to self-esteem and body image, family and friendship roles, financial resources and day-to-day activities. Because of these changes, you may experience a wide range of emotions including shock, fear, anger, sadness, thoughts about death, and helplessness.

However, when these feelings interfere with your ability to carry out normal daily functions, you may consider whether you are experiencing depression and/or anxiety. Some people experience depression and anxiety after a diagnosis of cancer, while others may already have a history of depression. Caregivers and family members may also experience depression and/or anxiety.

While it may be difficult, it is important to acknowledge whether you think you might be experiencing symptoms of depression and/or anxiety. If left untreated, depression and anxiety can impact your quality of life. For example, you may decide to skip doctors' appointments because you feel like you can't get out of bed or leave the house.

Talk with your health care team if you believe you are experiencing depression and/or anxiety to learn about treatment options. Treating emotional distress is just as important as treating your physical body. Do not neglect this important part of your care.

## **How Much Emotional Distress is Normal?**

Some signs or symptoms that might indicate professional help is required to manage feelings of depression and anxiety are:

- Sadness or worry so severe that you miss or postpone your treatment appointments
- Fear that leads to panic or an overwhelming sense of dread
- An inability to make decisions or difficulty concentrating
- Extreme irritability or anger
- Feeling despair or hopelessness
- Constant thoughts about cancer or death
- Feeling worthless
- Lack of interest in activities that previously provided pleasure
- Sleeping less than 4 hours per night or having difficulty getting out of bed
- Having no appetite for a period of weeks

## **Coping Tips**

- Talk to friends, family or spiritual advisors about your feelings and fears.
- Make an appointment with a counselor, therapist or psychiatrist to help deal with your thoughts and feelings.
- Join a support group.
- Ask your doctor about medications that can help.
- Focus on living in the moment.
- Use relaxation techniques to reduce stress.
- Engage in physical activity you enjoy several times a week.

## Value of Support

Cancer and its treatment may pose profound challenges to any individual or family. Yet, the idea of knowing you are not alone can be meaningful and significant in learning to cope with a cancer diagnosis. It is helpful to find people with whom you can share and express your feelings.

People cope with their emotions in different ways. Whether it is talking with a family member or friend, through individual therapy, or in the context of a support group, expressing emotions with others can:

- Decrease anger
- Improve self-confidence and assertiveness
- Improve an individual's expression of support, empathy, interest and humor
- Improve physical functioning
- Improve your overall quality of life
- Decrease feelings of isolation

## Cancer Support Helpline

The [Cancer Support Helpline](#) is staffed by mental health professionals who have over 170 years of combined experience helping people affected by cancer. They are available to provide emotional support as well as information and referral to local, regional and national resources to anyone impacted by a cancer diagnosis. CSC counselors and resource specialists can be reached by phone or [live chat](#) from **Monday through Friday, 9:00 a.m. – 9:00 p.m. Eastern Time**. All of our services are provided to you in English and Spanish.

# Identification, Intervention and Integration: Why Earlier Is Better

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This week, Real World Health Care brings you an interview with Paul Gionfriddo, president and CEO of [Mental Health America](#) (MHA), the nation's oldest mental health advocacy organization. MHA promotes mental health as a critical part of overall wellness, including prevention services for all; early identification and intervention for those at risk; and integrated care, services and support for those who need it, with recovery as the goal.

Since 1949, MHA and its affiliates across the country have led the observance of [May is Mental Health Month](#) by reaching millions of people through the media, local events and screenings. This year's theme is Whole Body Mental Health, focusing on increasing understanding of how the body's various systems impact mental health based on recent research.

We spoke about MHA's [B4Stage4](#) philosophy, the importance of behavioral health screenings, and the challenges facing patients and providers who are coping with behavioral health problems associated with chronic illnesses.

## Behavioral Health Screening

**Real World Health Care:** What is the significance of MHA's B4Stage4 philosophy?

**Paul Gionfriddo:** Until recently, mental illnesses were the only chronic diseases for which society waited for a public safety problem to manifest itself before action was taken. It was only once a person posed a threat to himself or to others that intervention was initiated. And that intervention usually involved police, lawyers, judges, and often, incarceration. We would never consider waiting until other chronic diseases like cancer, heart disease or MS reached Stage 4 to intervene, but we did with mental health diseases.

Mental illnesses are not simply public safety issues. They are chronic health conditions and should be treated as such. B4Stage4 is a call for everyone in society to look at the early warning signs for mental health problems and to act earlier in making health care decisions that will best promote recovery.



Paul Gionfriddo, president and CEO, Mental Health America

**RWHC:** What role does mental health screening play in the B4Stage4 philosophy, and how is MHA working to encourage and facilitate such screenings?

**PG:** Screening is crucial for early identification and intervention. The U.S. Preventive Services Task Force recommends regular behavioral health screenings for everyone over the age of 11. Adults are accustomed to regular screenings for blood pressure and cholesterol, and children are commonly screened for vision and dental problems, but we don't prioritize regular behavioral health screenings.

MHA offers a variety of online [mental health screening tools](#) (also available [in Spanish](#)) to help the general public, providers and caregivers open the doorway to recovery. These screening tools are the same ones physicians use, but they are self-administered, completely anonymous and provide customized recommendations on what to do next. Three thousand people take one of these screening tests every day, and to-date, more than three million people have been screened. The vast majority of those taking one of our online screening tests screen positive, even though they have not been diagnosed with a mental health condition previously.

## Chronic Disease and Behavioral Health

**RWHC:** Are people with chronic illnesses like cancer or MS at particular risk for developing behavioral health problems?

**PG:** About 80 percent of the people with chronic illness who take one of our online screenings test positive for a behavioral health issue. A common misperception about those with a chronic illness is that anxiety or depression is a “natural” part of having a chronic medical condition, that it “makes sense” to feel down or low. All of the focus is placed on treating the medical health condition and not the behavioral health condition.

We see two distinct groups for which this attitude is a problem. First are those who have chronic health conditions and are at risk for developing behavioral health conditions. For example, people who have had heart bypass surgery are at risk for chemical imbalances that can lead to depression. Second are those whose behavioral health conditions can lead to medical conditions, for example a person with depression who develops diabetes due to lack of exercise and proper nutrition, or even treatment side effects.

So many disease management programs fail because they focus on only the medical condition or only the behavioral health condition. The health care industry needs to better integrate services to focus on treating the *whole* patient.

## Integrated Behavioral Health Care

**RWHC:** What are some of the challenges facing health care providers treating those with chronic illnesses in terms of preventing or treating behavioral health problems that arise due to or after their illnesses?



**PG:** A key challenge is incomplete medical records. A primary doctor or medical specialist may not have visibility into the *whole* patient and may not have the time or training to efficiently incorporate behavioral health screening into their practice. They should know that screening doesn't need to be a long, involved process. The tests are simple to use and easy to score. The PHQ9 test for depression, for example, contains just 10 multiple choice questions. The CAGE-AID test for alcohol or substance abuse contains only four multiple choice questions.

We also encourage patients to take our online screening tests before seeing their primary doctor or specialist and to bring their results to their appointment for discussion. They can even do it on their phone in the waiting room and bring it right into the exam room.

Another challenge is lack of awareness about referral sources among primary and specialty physicians. MHA is working to make sure that localities throughout the country have the programs and services needed, through support centers and peer drop-in centers. We have also launched a [certified peer specialist program](#) to help support and work alongside health care teams in clinical and social services settings. This program is helping to reduce recidivism and readmission rates and improve overall well-being among those with even serious mental illnesses.

We're also working with patient advocacy organizations across a wide range of medical disease conditions to improve collaboration so that people are exposed to every available resource.

**RWHC:** Do you have any additional insight or advice to offer patients, providers or caregivers?

**PG:** The intersection of chronic medical illness and chronic behavioral illness is a significant one. My biggest piece of advice is: Don't be afraid to ask. If you have a behavioral health problem and also are experiencing physical symptoms, talk to your behavioral health care provider about them. If you have a medical health condition and think you may be at risk for a behavioral health issue, talk to your doctor and search out resources that may be available through the patient advocacy organizations for your diagnosed medical condition. See what they have to offer in terms of behavioral health resources.

I encourage patients, providers and caregivers to visit our web site for more information on [finding help](#) as well.

# Caregiver Conundrum: Supporting the Psychosocial Needs of the Cancer Support System

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This week, Real World Health Care is delighted to highlight the [American Psychosocial Oncology Society](#) (APOS). We spoke with APOS President-Elect [Vicki Kennedy](#), LCSW, executive director of Oncology Strategy & Patient Engagement at Cullari Communications Global. Ms. Kennedy shared insights on how APOS is addressing the psychosocial needs of cancer patients and caregivers alike.

## Access to Quality Psychosocial Care

**Real World Health Care:** Tell us about the overall mission and goals of the American Psychosocial Oncology Society.

**Vicki Kennedy:** The mission of APOS is simple— APOS aims to advance the science and practice of psychosocial oncology with the idea that we strive for a nation in which all people affected by cancer have access to quality psychological and social care to optimize their quality of life and health outcomes. We believe cancer and the ability to live well, no matter what the outcome of the illness, is much more than the biology of the disease. It is about the psychology and the social supports that impact the entire system around the individual with cancer. If we do not attend to the emotional, social and practical needs of patients with cancer and their families, we have not truly delivered the best cancer care.



Vicki Kennedy, LCSW, President-Elect, APOS

Founded in 1986, APOS creates a multidisciplinary forum for the exchange of research and clinical practice expertise among many different types of psychosocial oncology professionals—psychology, social work, psychiatry, physicians, nursing, public health, etc. We focus on both the science and the art of helping people with the emotional side of healing and the integral role of psychosocial health and well-being in oncology treatment and survivorship.

We were saddened at the recent passing of the founder of APOS, [Dr. Jimmie Holland](#), a renowned psychiatrist at Memorial Sloan-Kettering Cancer Center and the ‘grandmother’ of psychosocial oncology. Dr. Holland’s vision was that there would be a professional organization not only committed to bringing together all the disciplines that comprise the cancer care team, but also to advocate that caring for the whole person (and their family) makes a difference to their quality of life, health outcomes and ultimately the cost of health care.

## **Elevating the Profession and the Needs of Everyone Impacted by Cancer**

**RWHC:** How does APOS address psychosocial care for caregivers of cancer patients?

**VK:** There are millions of family caregivers caring for someone with cancer today. Caregivers play an increasingly important role in helping their loved ones with the day-to-day demands of facing cancer including how to navigate today’s complex health care system. They provide physical care, emotional support and logistical management, which can place a huge burden on them. It’s important for both researchers and clinicians to work together with patients and their caregivers to gather evidence about these challenges and create solutions that address these pressures and demands.

APOS creates a place where researchers and clinicians come together to discuss and explore this intersection of research and practice. We want to be sure that the interventions and programs being offered in cancer centers, community organizations and private practices where we work are impactful and based on scientific evidence that it helps patients and caregivers to achieve optimal wellness even in the face of sometimes devastating illness. Our goal through education, training and creative partnerships is to ensure that people can find mental health and other support services across the country. This goal is not just because we feel this is the right thing to do; it is deeply rooted in scientific evidence that attending to the distress that patients and caregivers face related to emotional coping, personal relationships, practical and financial worries will lead to better health outcomes. And, if cure is no longer an option, ensuring that patients, caregivers and families receive state-of-the-art physical and emotional support along the journey.

At the APOS [annual conference](#) this year in Tucson, researchers and clinicians presented on a host of topics such as caregiver distress; survivorship; management of depression and other psychological trauma; health equity and the unmet needs of diverse populations; etc. We focused on cancer across the lifespan for both patients and caregivers. Throughout the year, we host educational [webinars](#) by some of the top experts in the field on a variety of topics as well as we recently launched a [Psychosocial Oncology Institute](#) that provides training in psycho-oncology for many disciplines. Finally, APOS has a peer-reviewed, highly esteemed journal called the

Journal of Psycho-Oncology, where the latest science and information about evidence-based practice is published.

## Caregiver Challenges

**RWHC:** What psychosocial challenges are common among caregivers of cancer patients? How can those challenges best be addressed?

**VK:** The hard part is that many caregivers don't identify themselves by that term. They're simply doing what they know to do and don't imagine that it is a defined role. And yet they are challenged to balance the demands of caring for their loved one who is ill or recovering while caring for themselves, other family members and work or school responsibilities. Caregivers often experience personal distress as they worry about finances and just managing day-to-day life and often don't pay enough attention to their own health and well-being. It's common to feel overwhelmed in the role of caregiver and to need education and support to feel more confident and supported in the role, even in terms of logistics such as managing transportation to and from treatments and clinic appointments and making sure the patient takes their medications on time. It can be a heavy load and often caregivers are forgotten in the overall health care system.

These challenges can best be addressed by helping the caregiver know that, as clinicians, we care about *their* health and well-being in addition to that of the patient. Thanks to years of research and better understanding about the stress of caregiving, we are more attuned to caring for the person who is coming to appointments with patients — the person that patient identifies as the most important to them — and helping that caregiver access available resources to address their emotional and physical concerns. Those resources may come in the form of a social worker or support group, or in referral to a psychosocial specialist or community-based organization. No longer is the patient treated for cancer in a vacuum; we must address the network of people around the patient and especially the person who is assuming much of the responsibility for caring for the patient at home. This is challenging in a busy cancer clinic where the number of patients and caregivers is exponentially growing every day. At APOS, we are working across disciplines to create effective and efficient services and programs that help the system meet these needs, to ensure that cancer treatment continues on a timely, uninterrupted flow, and to help people help themselves throughout the journey.

Just as we now think of the “total patient” in terms of cancer care, we also need to think about the “total family.” Cancer is a family disease and requires commitment to making a difference. It is satisfying to see that the caregiver movement is continuing to grow. There are organizations such as the National Family Caregiving Association and others including APOS, that are standing up for the needs of cancer caregivers. An interesting, award-winning global campaign was recently launched called Embracing

Carers that aims at elevating that we in health care as well as society must not ignore the pressures and concerns of millions of family caregivers across the globe.

## Integrated Care

**RWHC:** How can the health care industry better integrate to address the special psychosocial needs of both patients and caregivers? What can psychosocial oncology professionals do to ensure that patients and caregivers get what they need?

**VK:** I believe there has never been a more crucial time in health care to elevate social, emotional, psychological and practical needs of cancer patients and their caregivers as well as the role of the psychosocial oncology professional. In over 35 years' experience, I have worked from the bedside at a major cancer center, participated in psychosocial research and publications, led program development and clinical management for a global patient advocacy organization and facilitated several non-profit boards in strategic planning and business development. In my current role as a health care consultant, I am keenly aware of the rapidly changing environment in oncology and the pressure points it creates for our patients, our health systems and our very professional survival.

While we are seeing advances in cancer treatment at an unparalleled pace, we as psychosocial oncology professionals are challenged to demonstrate the value we bring not only in improving quality of life and enhancing health outcomes but importantly, in **reducing the overall cost of care**. Let's face it—the challenges we are facing a nation in health care are many. Programs and services that do not address the 'bottom line' are often cut or seen as 'nonessential'. We need the data and tools to make the case with our institutions and the health care system to why treating the *whole* patient (and family) is a quintessential part of value-based, personalized cancer care.

We must continue to elevate the voice of the patient AND caregiver to ensure that cancer care attends to the whole person especially in the vital conversations that are happening in health care right now. We can help patients and caregivers transform their cancer experience and survivorship and find optimal health and well-being no matter what the outcome of the disease. We can make it possible for patients to receive the optimal benefit from outstanding, albeit increasingly complex, cancer treatments. In the words of our founder, Dr. Jimmie Holland, it is caring for the 'human side of cancer' that defines the highest quality cancer care.

# Psychosocial Care for Children with Cancer

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This week, Real World Health Care brings you an interview with [Lori Wiener](#), PhD, DCSW, LCSW-C, Co-Director, Behavioral Health Core and Director, Psychosocial Support and Research Program, [Pediatric Oncology Branch](#), [Center for Cancer Research](#), [National Cancer Institute](#). We asked Dr. Wiener to talk about psychosocial problems facing children with cancer and their families and how the Center for Cancer Research is addressing their needs through studies and other resources.

## Psychosocial Support and Research Program

**Real World Health Care:** Tell us about the mission and goals of the Psychosocial Support and Research Program at the Center for Cancer Research.

**Lori Wiener:** The mission and goals of the pediatric psychosocial support and research program at the Center for Cancer Research are to: 1) conduct studies and develop new measures to identify the psychosocial effects of cancer and other chronic illnesses in patients participating in clinical trials and protocols; 2) provide and evaluate clinical interventions and educational services developed to help patients and their families prepare for and cope with the effects of cancer and other related medical conditions; and 3) to disseminate research findings beyond the NIH and demonstrate leadership in the field of psychosocial effects of chronic illness.



Dr. Lori Wiener, National Cancer Institute

**RWHC:** How did you become interested in the field of psychosocial care for cancer patients?

**LW:** I began my training working with children and their family members in a community center in upstate New York and continued my training and work with children and families in outpatient mental health, residential treatment and private practice settings. I felt compelled to find more meaning in my work and accepted a position at Memorial Sloan Kettering Center (MSKCC). It was at MSKCC where I learned about the field of psycho-oncology – and at the National Cancer Institute about the many facets that comprise excellent psychosocial care for children and adolescents living with cancer and their family members.

I have witnessed, over and over again, the impact of serious disease on the child, adolescent, and young adult and concurrently, the impact of a serious childhood illness on the parents, siblings, grandparents, relatives, and the community of friends. It is an honor to do this work and I have been permanently moved by the love, devotion, tenacity, courage, strength, and compassion of children and families under extraordinary stress.

## **The Impact of a Cancer Diagnosis**

**RWHC:** What are some of the biggest psychosocial problems facing both children with cancer and the parents and families of those children?

**LW:** The diagnosis of cancer will have an immediate and potentially life-altering impact on the psychological, social, and emotional health of the entire family system. Following the immediate fear of questioning whether their child can survive the cancer diagnosis, families are tasked with learning complex medical terminology, exploring treatment options, rearranging work responsibilities, and re-prioritizing daily tasks. The child may experience painful or distressing treatments, procedures and side effects and adhering to therapy can be quite difficult.

Caring for a child with cancer often requires time spent in the hospital away from home and work. Families often experience cumulative financial hardship from travel expenses, temporary housing, medications, and treatment copays that can accumulate. Efforts must be made to help children to maintain their academic achievement during cancer therapy. Being separated from their peers and social support can be challenging, especially as children will also experience changes in their physical appearance.

Siblings of children undergoing cancer treatment are also exposed to significant stress as they are often separated from their family due to the geographic distance of the treatment center from home, resulting in decreased contact with family members and disruptions in their day-to-day routine while worrying about the health of their ill sibling. Grandparents also suffer. They observe the suffering of their grandchild, and also the suffering of the child's parent having to go through such a challenging experience. If the sick child has a sibling, grandparents also worry about seeing their other grandchildren worry for their sibling and the consequences of the illness on their lives.

Children who complete treatment for cancer are at risk of both medical and psychosocial late effects in survivorship. Continued monitoring of their health is essential. As their personal outlook may have been altered by their cancer experience or limitations due to cancer therapy, there might be changes to their life plans and goals. If there is a relapse, more treatment is needed with increased uncertainty about the future.

If the child does not survive, families experience significant physical, emotional, social, and spiritual distress.

Helping families cope with impact on lifestyle, education, employment, siblings, and family relationships all fall within the scope of psychosocial care.

**RWHC:** How can all of those challenges be best addressed by both clinicians and the patients/families themselves?

**LW:** Comprehensive psychosocial care begins with early assessment of family strengths and vulnerabilities and incorporates a range of therapeutic interventions, utilizing interdisciplinary resources to meet the needs of all family members. Interventions and strategies must be aimed at identifying the continuum of coping responses, building on family strengths, assisting families with special needs, and enhancing adaptive coping skills. Each of these are essential to facilitating both family growth and survival through the crises generated by childhood cancer and should continue throughout and beyond the course of the disease into survivorship or bereavement. Family centered care, having the child and parents be included as members of the treatment team, is essential. This requires an ongoing multidisciplinary approach to the psychosocial care of children and adolescents and their families.

## **Voicing My CHOICES™**

**RWHC:** Tell us about the Voicing My CHOICES™ study you're conducting. What are its goals?

**LW:** Discussing end-of-life (EoL) care is very challenging for young adults (YA) living with a life-threatening disease. While many helpful documents exist to facilitate EoL conversations with adults, few resources exist to aid YA in understanding and accepting their changing physical, emotional and social needs when treatment is no longer effective. Between 2007-2011, our team explored the helpfulness of Five Wishes with adolescents and young adults living with HIV or advanced cancer. This research led to the development of a new advance care planning (ACP) guide, Voicing My CHOICES™ (VMC). However, *Voicing My CHOICES™* had not been empirically examined in its completed form.

The objectives of the current study are to determine the perceived helpfulness of VMC and to determine whether engaging in advanced care planning using VMC is associated with reduced anxiety, improved social support, increased acceptance of illness, and/or improved communication about ACP with family, friends, and/or health care providers.

The study is open to participants ages 18 through 39 years living with cancer or another chronic illness. Each subject completes a baseline assessment of their anxiety pertaining to advance care planning, quality of social support, acceptance of illness, and quality of communication with family, friends and health care providers. Then they review Voicing My CHOICES™, and comment on each section as to whether it can provide an opportunity to address ACP needs for themselves and for other YA their age living with a serious illness.



At 1-month, we re-assess the utility of the document, anxiety, quality of social support, acceptance of illness, communication about EoL planning, and whether the patient participant has shared any of the work completed in the document with a family member, friend, or health care provider. If the participant had shared preferences that were documented in *Voicing My CHOICES™* with a family member or friend, and had consented for us to contact that person, we complete a brief interview with the family member or friend to assess the helpfulness and limitations of *Voicing My CHOICES™* for ACP. If the participant shared the ACP preferences that were documented in *Voicing My CHOICES™* with their health care provider and had consented for us to talk with that health care provider, a brief interview is conducted with their health care provider to assess the helpfulness and limitations of *Voicing My CHOICES™* for end-of-life planning and whether any changes in the participants' health care were made in response to *Voicing My CHOICES™*.

## **Additional Resources**

**RWHC:** Are there any National Cancer Institute resources you'd like to highlight for clinicians, patients, families or support communities who would like to know more about pediatric psycho-oncology?

**LW:** *Standards for Psychosocial Care for Children with Cancer and Their Families* details 15 evidence-based standards for pediatric psychosocial care. It was inspired and supported by the Mattie Miracle Cancer Foundation and was developed by pediatric oncology psychosocial professionals in collaboration with an interdisciplinary group of experts and stakeholders.

**ShopTalk** is a therapeutic game designed to help therapists communicate with pediatric patients (ages 7-16) about difficult emotional issues. ShopTalk has 3 versions: 1) pediatric patients, 2) siblings, and 3) children whose parents have cancer. The game has been distributed throughout the US and in 14 countries.

*This is My World* is a psychotherapeutic workbook for therapists working with children diagnosed with a chronic and a potentially life-threatening illness.

*Katie Finds Her Courage* tells the story of a child who learns about having NF1 and demonstrates the courage she finds to share her diagnosis with her classmates. An online version is being considered.

I also recommend the following:

Abrams, A, Muriel, AC, Wiener, L. (Eds) *Pediatric Psychosocial Oncology: Textbook for Multi-Disciplinary Care*, Springer International Publishing Switzerland, 2016.\_

Wiener, L, Pao, M, Kupst, MJ, Kazak, A, Patenaude, A, Arceci, R. (Eds). *Quick Reference for Pediatric Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management*, 2<sup>nd</sup> Edition. Oxford University Press, 2015.

# Oncology Social Workers Play Important Role in Cancer Care

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Real World Health Care is delighted to shine a spotlight on the [Association of Oncology Social Workers](#) (AOSW) and its [Patient Centered Research Collaborative for Psychosocial Oncology](#) (PCRC). We spoke with the PCRC's Project Lead, [Bradley Zebrack](#), PhD, MSW, MPH, FAPOS. Dr. Zebrack is Professor at the [University of Michigan School of Social Work](#) and also with a member of the Health Behaviors and Outcomes Research Program at University of Michigan [Rogel Cancer Center](#).

## Engaged Community

**Real World Health Care:** What are the goals of the PCRC?

**Bradley Zebrack:** Our purpose is to establish an engaged community of oncology social workers, patient advocates, academic researchers and key stakeholders in research of relevance to patients and families. Our vision is to assure that cancer patients and their families access and receive care that is safe, efficient, effective, timely, patient-centered and equitable.



Dr. Bradley Zebrack, University of Michigan School of Social Work

**RWHC:** How will PCRC achieve those goals?

**BZ:** Our intention is to create an innovative, productive and sustainable research network that fosters collaboration among experienced researchers, skilled psychosocial care providers, and informed patient advocates.

We're working to enhance our ability to conduct research and use research findings to influence cancer care. One way we're doing this is by conducting a series of face-to-face meetings and monthly teleconferences that engage and utilize our collective knowledge, talents and experiences.

## Research Priorities

**RWHC:** What sort of research is PCRC focused on?

**BZ:** We spent much of our first year generating and prioritizing patient-centered research by identifying highly relevant topics and issues intended to ensure and enhance the quality of cancer care. A survey of our membership uncovered a number

of priorities, including understanding the patient experience; palliative care, end-of-life care, and advanced care planning; distress screening; patient uptake of psychosocial support services; and mental health disorders and well-being.

## **Primary Providers of Psychosocial Care**

**RWHC:** How are oncology social workers uniquely positioned to help address the psychosocial care of cancer patients and their families?

**BZ:** Social workers provide 60-70 percent of all mental health services in the United States, and oncology social workers are the primary providers of psychosocial care for cancer patients. Many are trained and well-positioned to influence cancer care delivery by participating in their institution's cancer committee, where clinical care policies are deliberated, or by contributing to the generation, dissemination and implementation of evidence to inform patient-centered care.

**RWHC:** What challenges is the profession facing?

**BZ:** There are misconceptions about the role of social workers in health care settings. For example, some assume that social work is not an evidence-based practice. Another challenge is the lack of insurance reimbursement for social work services. There's also a social stigma about using mental health services, despite evidence supporting its efficacy and benefit for patients and families.

## **Integrating Supportive Care Services**

**RWHC:** How can patients and their families best make use of oncology social workers? What role should clinicians play in integrating the services social workers provide?

**BZ:** Cancer care systems need to do a better job integrating evidence-based supportive care services so they are available to patients. This is best done through collaborative care models in oncology, in which social workers are part of a multi-disciplinary team focused on identifying and responding to patients' needs and supporting their adherence to standard protocols.

The positive effects of psychosocial care for cancer patients and their families are well documented in terms of enhanced patient outcomes, medical cost offsets, and even survival. Despite the evidence demonstrating the effectiveness of psychosocial interventions for cancer patients, shortcomings and disparities exist in the delivery, targeting and tailoring of psychosocial support services to those that need them.

# Oncology Distress Screening: Integral to Patient-Centered Care

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*By Jeffrey Kendall, PsyD, Director of Oncology Supportive Care, University of Minnesota Cancer Center*

Oncology professionals and organizations around the world have come to realize the diagnosis and treatment of cancer can evoke significant levels of distress for cancer patients and their families. The Institute of Medicine's 2008 report, Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs, called attention to the importance of addressing the psychological and social problems associated with cancer and that leaving these need unmet could result in ". . .additional suffering, weaken adherence to prescribed treatment, and threaten patients' return to health."

Recognizing the critical need to assess and address the emotional and social concerns of oncology patients, the National Comprehensive Cancer Network (NCCN) issued a consensus statement recommending distress screening and management as a standard of care within oncology health services delivery. The term "distress" is used because:

- it is less stigmatizing to patients and families than psychiatric diagnoses or psychological jargon,
- it supports an understanding that distress is a normal process which ranges from mild to debilitating, and
- it facilitates recognition that distress severity can change across the cancer continuum.



Jeffrey Kendall, PsyD, Director of Oncology Supportive Care, University of Minnesota Cancer Center

In 2012, the American College of Surgeons Commission on Cancer (CoC) added distress screening to its accreditation standards for cancer programs. These standards are designed to help accredited programs focus on patient-centered care with the goal of improving the quality of cancer care throughout the United States. Standard 3.2: Psychosocial Distress Screening states:

*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.*

To comply with this standard, cancer programs are required to screen cancer patients at least once during a pivotal medical visit over the course of treatment. The mechanism and method for distress screening is determined by the cancer program.

Common approaches range from self-report patient questionnaires to clinician-administered questionnaires to clinical interview. The CoC prefers that patients are screened using standardized, validated instruments with established clinical cutoffs.

Despite this progress, distress continues to be under-detected and under-treated. When not addressed, distress has been shown to contribute to a number of negative patient outcomes including increased suffering, decreased quality of life for both patients and family members, reduced adherence with medical treatment, frequent and longer hospitalizations, and decreased survival odds.

## **How Big is the Problem?**

It is now accepted that 25-50% of all cancer patients experience significant levels of distress.<sup>1-3</sup> Among these patients are two sub-groups: those who meet the criteria for psychiatric illnesses such as major depression, PTSD, or adjustment disorders (up to 25% of all patients), and patients who report distress levels that do not meet criteria for a psychiatric diagnosis but experience distress that significantly interferes with quality of life and functional status (15-20% of all patients).<sup>1-3</sup> Using the term “distress” allows cancer programs to identify patients who fall into either of these two groups and provide interventions to reduce suffering and improve quality of life. It is important to remember distress and its intensity may fluctuate over the cancer trajectory. Distress levels may increase with recurrence, advanced disease, increased pain, disability, and symptom burden.

## **Screening Instruments**

The difficulty cancer programs are facing in screening for distress might lead to an assumption that there is a lack of screening instruments that are brief and easy to administer, score, and interpret. Fortunately, this is not the case. There are many different types of screening instruments available to cancer programs. Among those most commonly used are:

### ***NCCN Distress Thermometer***

Endorsed by the NCCN Distress Practice Guidelines panel, this tool consists of a single item asking patients to rate their distress using a vertically aligned (thermometer) visual analogue scale with scores ranging from 0 (“no distress”) to 10 (“extreme distress”). The NCCN Clinical Practice Guidelines for Distress Management added a 34-item problem checklist to the Distress Thermometer to help in identifying the source of the patient’s distress.

### ***Edmonton Symptom Assessment Scale (ESAS)***

The Edmonton Symptom Assessment Scale (ESAS) is a brief screening instrument developed for use with palliative care patients and validated with oncology patients. It consists of nine visual analogue scales for patients to rate the severity of the following nine symptoms: pain, activity, nausea, depression, anxiety, drowsiness, lack of appetite, well-being, and shortness of breath.

## **Screening Implementation: More Than Just a Screening Tool**

For cancer care providers, selecting a screening tool and establishing a screening process are essential first steps, but they are only the beginning of developing a distress-screening program. Positive screens require an assessment by the appropriate psychosocial professional to determine the frequency, intensity, duration, and functional impact of the distress. The assessment may reveal the need for intervention and/or referral. After intervention, follow-up and further evaluation are needed ensure that the patient's distress is minimized or eliminated.

Some cancer programs have internal professionals to assist in the assessment, intervention, and follow-up components of a distress-screening program. For example, patients might be referred to dietitians, social workers, psychologists, pharmacists, financial navigators, or specialists in spiritual care, palliative care, and rehabilitation—just to mention a few. However, even with in-house psychosocial professionals available, the procedures associated with referral, communication, and follow-up can be significantly challenging. Cancer programs that do not have oncology-trained psychosocial professionals available may work with resources in the community, including local social service organizations and universities, to develop a referral network that can help address distress.

A number of national organizations offer resources, tools, and peer-to-peer insights on support for establishing and improving cost-effective distress-screening programs for patients with cancer, including but not limited to the Association of Community Cancer Centers; American Psychosocial Oncology Society, Association of Oncology Social Work, American Society of Clinical Oncology, American Cancer Society, Leukemia and Lymphoma Society, and Cancer Support Community. Even pharmaceutical companies can provide resources for cancer patients within individual cancer centers.

### **Lessons Learned**

The distress screening instruments should be brief; easy to administer, score, and interpret; and be non-stigmatizing to patients. Cutoff values and specific validity and reliability data should be empirically established. Distress screening is the most effective when the screening instrument is embedded within the electronic health record (EHR) and patients are screened prior to their caregiver appointments. This allows easy administration, reliable results, and immediate feedback to patients. Further, when positive screening scores create automated referrals to the appropriate psychosocial provider through the EHR, efficiency is maximized.

Finally, cancer programs need adequate staff to determine which screening instrument to use, develop the screening policies and procedures, evaluate and interpret the screening instrument, and develop the appropriate interventions and/or referrals. Anecdotally, we have found that the distress-screening process is helping us to uncover patient problems at an earlier point thus facilitating problem solving while these problems are still manageable.

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Jeffrey Kendall, PsyD, is Director of Oncology Supportive Care for University of Minnesota Cancer Care. He serves on the Education Committee for the Association of Community Cancer Centers (ACCC), and served on the Advisory Committee for the ACCC Distress Screening education project, conducted in partnership with the American Psychosocial Oncology Society (APOS).

# Community Cancer Practices Tackle Behavioral Health Concerns

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This week, Real World Health Care brings you an interview with Robert “Bo” Gamble, director of strategic practice initiatives, Community Oncology Alliance (COA). COA is the only organization dedicated solely to community oncology, where the majority of Americans with cancer are treated. We discussed the importance of allowing cancer patients to receive quality, affordable and accessible care in their own communities and how the COA is addressing the needs of community cancer care through Oncology Medical Homes and its Advanced Practice Provider Network.

## Behavioral Health & the Oncology Care Model

**Real World Health Care:** What are some of the biggest challenges community oncology practices face in treating the behavioral health needs of their patients?

**Bo Gamble:** For cancer patients, having care that’s close to home is especially important. One of the biggest challenges and a key focus of COA is to keep local cancer care teams in community practice settings and minimize their migration to larger academic and teaching hospitals. COA provides an important support structure for integrated community cancer care teams, including physicians, advanced practitioners, nurses, pharmacists, and practice managers. With the right support, community cancer practices have more time to focus on patients’ emotional and behavioral needs in addition to their medical needs.



Robert Gamble, Director of Strategic Practice Initiatives, Community Oncology Alliance

From a patient-centered perspective, it’s about getting them the right care in the right place and at the right time. That extends to care for behavioral health, which is a component of the Oncology Care Model (OCM). Highly-coordinated care is a cornerstone of OCM, and we have a support network that helps community oncology practices succeed and thrive in implementing the OCM while managing increasingly complex services — including behavioral health services — and health care delivery pressures.

## Oncology Medical Home

**RWHC:** What role can the Oncology Medical Home (OMH) play in helping cancer patients get the behavioral health screenings and treatment they need?



**BG:** COA has pioneered policy on OMH, which is a patient-centered system focused on promoting, delivering, ensuring and measuring quality and value in cancer care. One of the support arms in this effort is the OMH implementation committee that identifies, reviews and recommends tools, technologies and templates to assist cancer care centers.

Patient engagement is an important domain within the OMH. Community cancer care teams must listen to patients and respond to all their needs, including medical, behavioral, spiritual and financial needs. The OMH concept also extends to detailed survivorship care planning, which is now starting to be addressed more directly in community cancer practices and involves a range of specialty care practitioners, including behavioral health professionals. Patients need to stay involved and connected with that survivorship care team.

## **Advanced Practice Providers Crucial in Community Settings**

**RWHC:** What role do advanced practice providers such as nurse practitioners and physician assistants play in helping cancer patients get the behavioral health screenings and treatment they need?

**BG:** Advanced practice providers (APPs) serve as clinical quarterbacks and often handle the bulk of patient communications and coordination, especially through survivorship care as I referenced just a moment ago. The COA has an Advanced Practice Provider Network that consists of a private, peer-to-peer information sharing website and listserv; monthly conference calls to review practice issues and discuss solutions; and opportunities for in-person meetings. The goal of the Network is to keep oncology APPs up to date on the latest news and developments including patient support strategies, health reform initiatives, the newest drugs and therapies, and APP leadership roles.

Increasingly, APPs are called on to manage everything from care team coordination to screening patients for distress issues that range from behavioral health problems, to clinical navigation and support, to local employers for the cancer care needs of their employees.

COA conducted a patient survey a few years back and, in virtually every category, APPs outscored physicians. That's because they're often more hands-on and tend to have an extra level of sensitivity and empathy so patients are more willing to open up to them.

## **Cancer's Financial Toll**

**RWHC:** How can community cancer practices help patients address the problem of financial distress?

**BG:** One of the first steps is to determine where the stress is coming from: Did that financial distress exist before the cancer diagnosis? The CMMI Oncology Care Model specifies that patients receive guidance on the expected total cost of care. It can be

difficult for community cancer physicians to accurately estimate the total cost of a patient's cancer care journey due to the many variables that may happen in the care process. But what should be communicated is the patient's out-of-pocket costs — not just for treatments, but also costs related to managing side effects, dealing with unexpected costs like emergency room visits, and costs associated with end-of-life care.

The cancer care support team assists in identifying these needs, investigating and then utilizing these resources to aid the patient and family with this burden.

This assistance and support is also demonstrated by being available to the patient 24 hours per day 7 days a week. This minimizes unnecessary emergency room visits and hospitalizations. The benefit to the patient includes reducing financial burden but oftentimes more effective and efficient cancer care.

From screening for distress and navigating resources to creating detailed survivorship plans, the community cancer care team can form real and lasting bonds with patients. Those bonds are sacred and cherished and they should be encouraged to grow.

# Biopsychosocial Care Vital to Well-Being of Cancer Patients

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This week, Real World Health Care brings you an interview with Jon Levenson, M.D., Associate Professor of Psychiatry at Columbia University Medical Center, and member of the American Psychiatric Association's Council on Consultation-Liaison Psychiatry. Dr. Levenson spoke about some of the challenges facing psychiatrists and integrated health teams when caring for patients with chronic medical problems such as cancer.

## Consultation-Liaison Psychiatry

**Real World Health Care:** What is the mission of the American Psychiatric Association's Council on Consultation-Liaison Psychiatry?

**Jon Levenson:** The Council focuses on the psychiatric care of people who are medically ill. It recognizes that the integration of biopsychosocial care is vital to the well-being of patients and their families, and that full membership in the house of medicine is essential to the well-being of psychiatry. We achieve our goals through initiatives related to research, clinical care, education and health policy, working closely with other physicians, residents and medical students.



Jon Levenson, MD, Associate Professor of Psychiatry, Columbia University Medical Center

## Medical Health Linked to Behavioral Health

**RWHC:** Behavioral health issues can strike just about anyone, but are there certain types of chronic medical illnesses that are particularly associated with a higher incidence of patients being at risk for developing behavioral health problems?

**JL:** Often, that link between medical and behavioral health problems depends on whether the medically ill patient has pre-morbid behavioral health problems. For example, if someone has a pre-existing complication such as an alcohol or opioid use disorder, they tend to be at higher risk of non-adherence to their medical treatment. Or, a long-time tobacco user diagnosed with throat cancer may need treatment for his or her nicotine addiction.

From the other perspective, there are certain medical illnesses, such as heart disease and cancer, that carry a heavy burden and come with various complications, which can lead to a higher risk of depression. When patients are first diagnosed with cancer, it can be very common to have acute emotional symptoms such as numbing, anxiety,

sleep disturbance and depressed mood for about 7-10 days. If these symptoms endure — and often, they do not — the concern is that the patient may develop acute psychiatric disorders including major depression, generalized anxiety disorder and a group of disorders called adjustment disorders.

We also can't discount the behavioral health problems associated with survivorship. The patient's cancer may be in remission, but they may continue to suffer from psychosocial complications, including marked distress around the anniversary of their diagnosis, surgery or end of treatment. For some, the end of treatment can be particularly challenging because they are not being as monitored as closely, which can produce anxiety around living with an uncertain medical future.

Other concerns that our profession focuses on include sexuality, intimacy and fertility issues among survivors and problems relating to re-entry back into normal life such as difficulties finding a job or obtaining medical insurance due to their pre-existing condition.

## Challenges for Care Teams

**RWHC:** What are some of the biggest challenges facing integrated health care teams in terms of making sure cancer patients receive the proper behavioral health screening and treatment?

**JL:** There are a number of issues, from ensuring that patients adhere to their oncological treatments to regularly screening patients for behavioral health problems using standardized programs such as the distress screening thermometer developed by the late Dr. Jimmie Holland or the [PHQ-9 Patient Health Questionnaire](#). These tools give cancer treatment teams an easy-to-use method for routinely evaluating the behavioral health of their patients, not just during active cancer treatment, but also during ongoing outpatient monitoring.

Our Council works closely with other organizations such as the [Academy of Consultation-Liaison Psychiatry](#) and the [American Psychosocial Oncology Society](#) to collaborate, share knowledge and develop programs that will help patients and their families navigate the behavioral health challenges associated with chronic and life-altering illnesses. For example, we're currently working on a position statement related to palliative care. We're intent on improving the knowledge base around end-of-life care and the role that psychiatrists play.

**RWHC:** Do psychiatrists have a hard time finding a “seat at the table” in integrated cancer care teams?

**JL:** Today, cancer care is whole-person care. Virtually every comprehensive cancer center has a psychosocial oncology program with staff that works closely with the medical oncology teams and palliative care teams treating patients.

Consultation liaison psychiatry is well immersed in the medical setting, and from that point of view, we all have a seat at the table. While there can be challenges, we work to

overcome them through training in acute and outpatient care settings with medical students, residents and fellows so they learn how to effectively develop and maintain that seat at the table. We work especially closely with medical students studying psychiatry to help them understand what consultation liaison psychiatry is and get them interested in the field, which enhances recruitment and long-term support for the field.

Consultation liaison psychiatrists are well-regarded advocates for patients and can help our medical colleagues understand how to screen for distress as well as get patients the support and therapy they need. Often, issues can be openly addressed and discussed with short-term psychiatric support that ameliorates the bulk of patients' fears, anxiety and behavioral distress.

## **Encouraging Patients to be Open**

**RWHC:** What advice would you give to a cancer patient who may be undergoing behavioral health problems associated with his or her cancer diagnosis, but who may feel uncomfortable or unsure about reaching out to a psychiatrist for help?

**JL:** First, they should know that help exists. If someone is suffering from acute distress such as debilitating anxiety, panic attacks or strong feelings of despondency, they should seek immediate help in the form of psychiatric support and pharmacotherapy. If they are hesitant to reach out directly to a psychiatrist, they can start by reporting their distress to their physician, nurse or someone else on their care team.

There are also a wide variety of patient support organizations — at least one for just about every disease in the book — that can provide information and support. Many of these organizations have “buddy programs” through which a newly diagnosed patient is partnered with someone who has been there before. These groups can help tremendously with feelings of isolation or differentness, and many offer both in-person and online support, so no matter where you live, help is only a click away.

# Childhood Cancer: Financial Distress Hits Families Hard

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This week, Real World Health Care focuses on emotional stress associated with childhood cancer. We hear from Jessica Cook, MSW, Patient & Family Services Coordinator for the [National Children's Cancer Society \(NCCS\)](#), about the services NCCS offers to help patients' families cope with the disease's devastating financial toll.

## Supporting Families

**Real World Health Care:** Tell us about the mission and goals of the NCCS.

**Jessica Cook:** The National Children's Cancer Society (NCCS) tirelessly and compassionately supports families making their way through the daunting world of childhood cancer. With over thirty years of experience serving nearly 42,000 children, the NCCS has become a master navigator of this world, helping families get where they need to be—physically, financially and emotionally. Distributing more than \$65 million to families over its lifetime, the NCCS is able to take a “no matter what” approach, creating a clear path through the labyrinth of childhood cancer and survivorship to help families stay strong, stay positive and stay together. Because no family should go through childhood cancer alone.



Jessica Cook, MSW, Patient & Family Services Coordinator, National Children's Cancer Society

The average cost to treat a child with cancer is over \$800,000. The financial and emotional impact a diagnosis has on the entire family is devastating. The NCCS seeks to help unburden some of the financial devastation. By providing transportation assistance, whether a family is local or needing to fly across the country, the NCCS ensures that the child is able to get to the life-saving treatment facility no matter what. For families having to remain in the hospital or relocated from home, we offer a one-time per year emergency stipend to help with expenses like meals while in the hospital, insurance premiums, household expenses, prescriptions, car expenses, and child care.

**RWHC:** What other types of support programs do you offer?

**JC:** In an effort to alleviate some of the behavioral issues children diagnosed with cancer face, we offer a mentorship program. Studies indicate that a mentoring program increases adjustment post treatment, reduces children's anxiety and increases both self-care skills and self-confidence. Our program connects young adult childhood cancer survivors with children who are currently in treatment. The mentor acts as a knowledgeable and experienced guide, a trusted ally and caring role-model throughout the school year.

## **Behavioral Health Challenges**

**RWHC:** Do children with cancer face unique behavioral health problems that aren't as prevalent in adults with cancer?

**JC:** Children with cancer may face unique challenges such as missing school, isolation from extended family and peers due to compromised immune systems, survivor's guilt, anxiety, depression, and difficulties in school.

**RWHC:** Do children with cancer have a difficult time accessing behavioral health treatments?

**JC:** The biggest challenges families face involve insurance coverage, geographic location and time. Frequently, facilities offer group work to help address some of the behavioral issues children and their families face, however many simply live too far or don't have the time to make another trip to the hospital and are unable to benefit from the resource. The NCCS recognizes the value of counseling for children with cancer and provides transportation assistance to ensure the child receives the support they need. It is important to note, that while initially children may experience anxiety and depression, decades of research on the impact of pediatric cancer and the psychological and emotional functioning of children indicate that a minority of youth demonstrate a long-term clinically relevant distress. In fact, the majority of cancer survivors show good psychological functioning.

## **Let Your Child Be a Child**

**RWHC:** What can parents do to help ensure that their financial distress does not add to the stress children are already under when they find out they have cancer?

**JC:** The most important thing that parents can do is allow their child to be a child. It is not the child's role to be a part of financial discussions especially as it relates to their diagnosis. When facing the financial challenges associated with their child's diagnosis it's important for parents to assess the personal impact the diagnosis will have on the family. Things to look at include loss of income, increased living expenses — such as child care and travel costs — and insurance coverage. The increased expenses can

seem overwhelming, but creating a monthly budget can help provide some understanding and control over their financial situation. Above all, it's important that families understand that they are not alone. There should be no fear or embarrassment when reaching out to resources, like the National Children's Cancer Society, to help with the costs associated with treatment, and in discussing any financial or emotional concerns with members of their child's treatment team.



# Strength In Numbers: How Peer Support Empowers Those Coping with Cancer

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*By Ashley Goodman, Executive Assistant & Social Media Manager, Kidney Cancer Association*

Online peer support groups are growing and it's easy to see why. Peer support groups offer those dealing with a difficult diagnosis such as cancer, the chance to find empowerment, support and guidance from other members who are going through a similar situation.

Inspire, which is an online patient-driven community, has grown to nearly 1.5 million members since its inception in 2005. The company has more than doubled its amount of registered users over the past three years. Of the 200 groups that can be found on the site about a third have joined one or more of the online community's cancer support groups.

"Inspire co-founder and CEO Brian Loew wanted to create a safe, supportive community for patients to gather, and if members wanted to participate in clinical trials, then Inspire could help connect them to researchers," said John Novack, communications director at Inspire. "We deeply believed from the start that we can accelerate medical progress, and as we've grown to more than one million members, we are helping to do just that."

## **Online Kidney Cancer Support Community**

In 2014, the Kidney Cancer Association joined Inspire to create an online community for those who were diagnosed with kidney cancer. Currently, the community has over 2,000 active members.

"As a kidney cancer patient, I know how valuable emotional support can be," said Kidney Cancer Association Vice President Bill Bro.

All in all, the Kidney Cancer Association has about 100,000 members on its social media pages in addition to its presence on Inspire.

"To my knowledge, the Kidney Cancer Association's Inspire community and Facebook groups constitute the largest kidney cancer support network anywhere in the world. Thousands of people are ready to offer their perspectives on treatment decisions as well as offer help to caregivers," Bro said.

According to Sara Ray, senior director of research at Inspire, peer support groups have a positive effect when it comes to patients making decisions and exploring all of their treatment options.

“The collective clinical and experiential knowledge of the peer support group helps patients not only learn which treatments are available, but what they can expect from those treatments,” said Ray. “Patients often feel those who are on the cancer journey have a ‘real-world’ understanding of treatments and are eager to learn from them. In addition, patients can learn about upcoming treatments and clinical trials. This knowledge empowers them to speak to their physician, learn more, ask better questions, and become active in treatment decisions.”

## **Changing the Face of Cancer Care**

Essentially, patient support groups are helping change the face of cancer care. Online support communities allow patients to make informed decisions with help from their peers.



Bill Bro, Vice President,  
Kidney Cancer Association

“Patients are smarter and more empowered,” Ray said. “Peer groups have become a way to crowdsource information. As ‘asking the hive’ becomes more and more popular, patients are able to use the combined knowledge and experiences of their peers to learn about new options, manage expectations, and take part in decision making.”

When it comes to the psychosocial aspect, online peer support communities offer a myriad of resources for their members.

“Inspire provides a place for patients to feel less alone or isolated by providing a place for those dealing with cancer to share their worries and concerns and receive validation, love, and support,” said Ray. “Further, Inspire provides a place where patients can brainstorm and plan, feeling empowered to make decisions. In addition, many patients and caregivers on Inspire express the desire not to burden loved ones by seeking emotional support. Inspire provides a place where patients and caregivers can express their fears, discuss their worries, or just vent in a space apart from their loved one. Often, communities have discussion channels specifically for caregivers.”

Ray also noted that with communities like Inspire, patients gain what they lack in cancer support.

“They can seek clinical information or emotional support,” she said. “If they have a rare cancer, they can find others like them. Peer support groups are not a one size fits all solution. They are just as effective for a patient who wants to check in only at times of testing and for the patient who visits the board daily to share side effect struggles. Moreover, patients gain a place to give back. Many patients enjoy ‘paying it forward’ by sharing their experiences and providing support to others.”

From a personal perspective, the Kidney Cancer Association has seen a direct impact with its patients within Inspire's community.

"I've witnessed patients moving from feeling hopeless to hopeful in just a few months as the result of positive interactions with others online," Bro said.

For more information on Inspire, go to [inspire.com](https://www.inspire.com). For further information on the Kidney Cancer Association, go to kidney [cancer.org](https://www.kidneycancer.org).

To join the Kidney Cancer Association's Inspire community, go to [kidneycancer.me](https://www.kidneycancer.me).

# Cognitive Behavior Therapy for Teens and Young Adults with Cancer

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This week, Real World Health Care focuses on the special behavioral health issues that can impact teens and young adults with cancer. We are delighted to share information on this topic from the [Association for Behavioral and Cognitive Therapies](#), and to feature insights from Tammy A. Schuler, PhD, a Licensed Clinical Psychologist and Director of Outreach and Partnerships for ABCT.

ABCT is a multidisciplinary organization committed to the enhancement of health and well-being by advancing the scientific understanding, assessment, prevention, and treatment of human problems through the global application of behavioral, cognitive and biological evidence-based principles. It seeks to decrease human suffering using science.

## Supporting the Cancer Community

**Real World Health Care:** How does ABCT address the special needs of adolescents and young adults with cancer?

**Tammy Schuler:** Adolescents and young adults (AYAs) and their families coping with cancer have a lot to deal with. The AYAs are dealing with a major, life-changing circumstance during a period of their life when they are also dealing with other huge changes and developmental milestones. ABCT provides a variety of information to this patient community on treatment for depression, anxiety, sleep, insomnia and other areas that AYAs may struggle with. We also offer a [clinical directory](#) in which people looking for cognitive behavioral treatment can find providers in their area. Some of these providers specialize in working with people and their families who are coping with cancer, and some of them specialize in working with young people coping with a range of concerns.



Tammy Schuler, PhD, Director of Outreach and Partnerships, Association for Behavioral and Cognitive Therapies

## Reaching Out for Help

**RWHC:** What advice would you give an AYA or family member who may feel uncomfortable or unsure about reaching out to a cognitive behavior therapist for help?

**TS:** Normalizing it is important. Many AYAs dealing with cancer experience some sort of cancer-related behavioral health issue. Issues may not happen right away. They may come up at some point during treatment or when they're recovering from cancer

treatment and trying to get back to their lives, and even beyond. In fact, a lot of AYAs report that they experience struggles after cancer treatment is over.

It's also normal for family members – especially caregivers – to experience a behavioral health concern, at any point after the AYA's cancer diagnosis.

Behavioral health concerns can range from having more difficulty adjusting to or coping with the cancer than one might expect, to ongoing feelings of sadness, anxiety, worry, panic attacks, persistent insomnia, increased substance use, and other symptoms. If a distressing behavioral health symptom sets in and doesn't let up, if a behavioral health symptom becomes really disruptive to day-to-day life, or if a person starts worrying that they might hurt or kill themselves, those are signs to reach out to a qualified therapist for help.

It's perfectly okay to reach out to people who can help, including cognitive behavior therapists, no matter what. Cognitive behavioral therapists are used to working with people dealing with these kinds of concerns; and the sooner someone reaches out, the sooner a plan can be developed to help the person feel better. Be sure to carefully check the credentials of the therapist. They should be licensed to practice in the patient's state and should be listed as members of professional organizations, such as ABCT or the American Psychological Association.

HealthWell's Cancer-Related Behavioral Health Fund is a wonderful initiative for insured people who want to reach out to a cognitive behavioral therapist, but who are struggling with finances.

## **Fast Facts: Adolescents and Young Adults with Cancer**

The following information has been excerpted from the full ABCT fact sheet, written by Glynnis McDonnell, Doctoral Candidate in Clinical Psychology at St. John's University and a Psychology Intern with the University of Tennessee Health Sciences Center & St. Jude Children's Research Hospital.

A cancer diagnosis can be upsetting for individuals of any age; however, the effects of a cancer diagnosis and treatment may be especially upsetting for people diagnosed as adolescents and young adults (AYAs). This period involves rapid physical and psychosocial development, and a cancer diagnosis can interrupt these developmental processes:

- Treatment often leads AYAs to take a large amount of time off from school or work, affecting career and education plans.
- Treatment can make the formation of romantic relationships difficult due to factors such as body image concerns, limitations placed on one's activities, etc.
- Treatment can lead to infertility, interfering with the ability to start biological families.
- A potentially life-threatening illness can be especially startling for AYAs:

- AYAs likely have a better understanding of the seriousness of their illness than child patients but are often unprepared to process the meaning of a serious disease as effectively as older patients.
- AYAs are still in the process of developing a stable sense of self. Therefore, diagnosis and treatment of a serious illness during this period could have a different psychological impact than it does for older adults.

There is growing evidence that cognitive behavior therapy (CBT) is an effective treatment for many of the psychological difficulties faced by AYAs. CBT is a form of psychotherapy that draws upon the connections among one's thoughts, behaviors and emotions. It cannot change the fact that this young person has had to cope with a difficult diagnosis, but it can help ease the related difficult feelings, including worry, sadness and guilt related to the cancer experience. It can also help the AYA process traumatic aspects of the cancer experience.

# “Triageing” Cancer and Behavioral Health Concerns

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This week, Real World Health Care shines a spotlight on Triage Cancer, a national, non-profit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials and resources. We spoke with Joanna L. Morales, Esq., CEO of Triage Cancer, who offered insights on how the concept of “triaging” can be applied to behavioral health issues associated with cancer.

## Collaborating to Help Cancer Patients

**Real World Health Care:** Can you tell us about the mission of Triage Cancer?

**Joanna Morales:** Triage Cancer believes that collaboration is the key to providing valuable information and practical tools on survivorship to the cancer community, particularly to its underserved members. To that end, Triage Cancer works with cancer community partners, healthcare professionals and other experts to connect people to relevant, practical and personal information on cancer survivorship issues, such as access to healthcare, treatment options, psychosocial care, survivorship planning, and the practical, legal and financial issues that arise as a result of a cancer diagnosis.



Joanna L. Morales, Esq, CEO,  
Triage Cancer

## Navigating a Cancer Diagnosis

**RWHC:** How does the concept of triaging relate to being diagnosed, living with and surviving cancer, including related behavioral or mental health issues?

**JM:** Triaging is the process of determining the priority of patients’ treatment based on the severity of their condition. When someone is dealing with a cancer diagnosis, there is information to learn, things that need to be dealt with, and decisions to make. Trying to juggle it all can be incredibly overwhelming. Our goal is to provide access to quality information about all types of cancer survivorship issues that may arise after a diagnosis. Armed with that information, individuals not only get the big picture of how to reach their end goals, but they can better decide what needs to be handled first and what can wait until later – the very definition of triaging.

With behavioral health issues associated with cancer, it’s about deciding what you can do for yourself and in which order those actions will best serve you. With a cancer

diagnosis comes side effects and difficult decisions regarding treatment, health insurance, financial issues and more. Dealing with these legal and practical issues can create stress and anxiety. There is also data that shows that individuals with a higher financial burden are more likely to experience depression. We offer education on how to effectively navigate these issues, to thereby decrease stress, anxiety and depression. We also provide tools on stress management and other psychosocial topics that impact mental health.

For example, we offer a [Don't Stress the Stress webinar](#) as well as a webinar on [Staying Healthy After Cancer: Behaviors You Can Adopt to Improve Your Health](#). We also offer Quick Guides and an educational blog on our [Resources page](#).

We have a [new webinar](#) coming up on November 15 that does a great job explaining what stress is and how it affects everyone differently. It will also provide simple, common sense and practical techniques to get stress under control. I encourage your readers to [register for the webinar](#).

## **Recognizing a Problem is Just the First Step**

**RWHC:** What do you think are some of the biggest challenges facing the cancer patient community when it comes to behavioral health problems?

**JM:** At Triage Cancer, we believe one of the biggest challenges regarding behavioral health is not being sure where to start looking for help. Recognizing a problem is just the first step. Finding answers can be hard, and taking action toward a healthier you can be even harder.

While health insurance coverage includes coverage for behavioral and mental health care, there are still likely to be out of pocket costs that you may be responsible for. If your budget is tight, consider financial assistance programs that may be available to you, rather than just skipping getting the help you need. Triage Cancer offers a separate website at [www.CancerFinances.org](http://www.CancerFinances.org), which provides information on how to navigate finances after a cancer diagnosis and connects you to financial assistance resources.



# Effects of Parental Cancer on Children and Adolescents

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*By Maryrose Mongelli, MSW, LMSW, Women's Cancers Program Coordinator, CancerCare*

Cancer is a chronic and sometimes terminal illness that impacts the person physically, emotionally and often financially. Time becomes a commodity, and the fragility of life becomes salient, often accompanied by an increase in humility and gratitude. Life often gets turned upside down; familial roles might change and a family may lose financial security. All family members may be affected by a loved one's cancer, and children are among the most vulnerable and susceptible to familial impacts. This article will briefly explore some of the psychosocial issues that children may experience when a parent or guardian is diagnosed with cancer.

## Difficult Emotions

Receiving a cancer diagnosis may elicit difficult emotions such as denial, anger, anxiety and/or depression, and these emotions may manifest in ways that psychologically affect children. Family members experience turmoil when a parent is diagnosed with cancer. A newly diagnosed individual will begin to contemplate how they will tell their family, and if the individual is a parent with dependent children, they sometimes struggle with how to explain cancer to their children. Some may not tell children that they have cancer. In fact, parents may avoid using terms associated with cancer, such as chemotherapy, radiation, surgery and even the word cancer itself around their children as a means to protect their child(ren) from distress, disruption in their life, as well as avoiding questions about cancer and death. Avoidance is a coping mechanism that people use to protect themselves from experiencing difficult emotions when they are not ready to confront and accept the reality of why they are having these emotions.



Maryrose Mongelli, MSW, LMSW,  
Women's Cancers Program  
Coordinator, CancerCare

## Be Open and Honest

For a parent/caregiver with cancer, talking with their dependent children is one of the most difficult conversations a parent can have, but being open and honest with their

child(ren) will help the child feel secure. Allowing the child(ren) to express their emotions and ask questions allows them to feel secure and grounded during an uncertain time. When a parent chooses not to disclose their cancer diagnosis to their child(ren), it is likely that their child will become confused and feel less secure when there are significant disruptions in their routine. Therefore, one can infer that parents often underestimate the level of their children's intuition.

## **Children are Perceptive**

Children are perceptive about the changes around them and will begin to question—whether internally or externally—any changes that occur, such as a significant change in the home environment, their own routine or their parent's emotional and behavioral state. Like any partnership, rapport and trust need to develop. A child-parent bond does not automatically happen. A parent must earn their child's trust even from birth. Children, especially young children, need to feel secure in their attachment to their parent/ caregiver. When a parent is emotionally absent, insecure attachment occurs, e.g. a mother's rejection of her child at birth. Moreover, when appropriate information is withheld from a child or adolescent their fundamental view of their parent becomes skewed. Young children may make assumptions that the cause of the changes/ disruptions occurring is their fault, and this may result in the child becoming anxious or depressed.

## **Structure and Routine are Key for Children**

A child thrives when their parents (guardians) provide structure and routine, and a cancer diagnosis can cause disruption to a child's routine. When first diagnosed, parents of dependent children are generally physically present, but psychologically less available to their children and their partners, due to their inability to be responsive to the child's/adolescents needs (Earley & Cushman, 2002), resulting from a cancer diagnosis. This may result in a change in family dynamics, e.g. children might become parentified. Parentification is the role reversal between the child and the parent/ caregiver, whereby the child becomes obligated to become the caregiver for their parent/caregiver, e.g. caring for younger siblings. If the child is an adolescent he/she may find employment to supplement the financial impact cancer has on the family.

As a result of parentification, adolescent truancy rates may increase and school attendance rates may decrease (Shah, Armaly, & Swieter, 2017). The parentification of children/adolescents prevents their personality, social, and emotional development. Poor social and emotional development may have significant impact on their future relationships. As a result, psychological issues that can occur in children when a parent is diagnosed with cancer or chronic illness are predominately adjustment disorders, anxiety, and depression. Based on a cohort study conducted by Wallin, et.al (2018), adjustment disorders were more common among children/adolescents aged 13 and older, keeping in mind that the psychiatric history of the parent with cancer did not modify the results.

## **Changes in Behavior**

As parents are mentally and physically distressed, they may not have the ability to identify that their children's behavior has changed. Changes in behavior in the home can often carry over into school or social environments. Children with a depressed or anxious mood may withdraw from activities, act out, and have diminished academic performance. Research shows that adolescents, especially adolescent girls, exhibit more psychosocial distress than pre-adolescent children. According to Welch, Wasdworth & Compas (1996), parents may be unaware of their child(ren)'s emotional distress, or have difficulty acknowledging it.

Children, not wishing to further burden their parents, may not express their emotions. The internalization of emotions among family members, such as parents not discussing cancer to spare their child or children internalizing their feelings to avoid burdening their parents, leads to a lack of communication.

## **Communication is Key**

In order to avoid misinterpretations or additional stress and anxiety within in the family when there is a cancer diagnosis, communication is key. Talking with children about their cancer diagnosis can be very distressing and is one of the most difficult conversations to have, and the first step is by using the word CANCER. As with any situation when talking with children it is best to talk in terms that their child(ren)/ adolescents can understand e.g., "special medicine." Parents can reassure their children that the cancer is not their fault, as well, giving them an opportunity to ask questions. Involving children in ways they can contribute to the parent's treatment can be accomplished by assigning age appropriate tasks. Also, it is important to discuss the changes that may occur during treatment. Finally, reassure the child(ren) that they will always be cared for.

Although difficult during a time of great distress, communication allows the family to maintain stability within the unit by reducing misunderstandings, arguments, and fear. Within a family unit, stability or family homeostasis, is considered the family "NORM." Considering that all families are different, ideally stability would be when all family members feel supported and nurtured. Stability within the home may combat a sense of insecurity. Insecurity may increase anxiety and depression among the family members and negatively impact the psychosocial functioning of children and adolescents. In order to mitigate feelings of insecurity and instability stemming from a cancer diagnosis, ideally a patient's treatment plan would include psychoeducation about how cancer affects the family. In addition, the patient's treatment plan could include family counseling and psychological intervention if necessary. Children and parents are equally affected by cancer, and employing all resources available can achieve stability in a potentially unstable situation.

## About the Author

Maryrose Mongelli, MSW, LMSW, is Women's Cancer Program Coordinator with CancerCare. She provides supportive counseling and resources to patients, caregivers, loved ones, and to those who have experienced the loss of a loved one. She is a part of the CancerCare for Kids program and is also affiliated with the National Association of Social Workers (NASW).

## About CancerCare

Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Its comprehensive services include counseling and support groups over the phone, online and in-person; educational workshops; publications; and financial and co-payment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts. To learn more, visit [www.cancercare.org](http://www.cancercare.org) or call 800-813-HOPE (4673).

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# Young Adult Cancer Survivors Need Special Support

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*By Jean Rowe, LCSW, OSW-C, CJT,  
Associate Director of Support Services,  
Young Survival Coalition*



Jean Rowe, Associate Director of Support Services, Young Survival Coalition

Young adults are at a certain stage of life development when diagnosed with cancer. They may be thinking about career decisions (i.e. do I stay in this job, go back to school or seek something new), where they want to live (e.g. hometown or move to another city), independently living on their own, and deciding what kind of mate they desire. They are not thinking about their lives being turned upside down by a cancer diagnosis.

All too often young adults are told “you’re too young” to have cancer when a concern is raised. This can result in late diagnoses and more advanced disease stage.

Young adults diagnosed with cancer experience interrupted lives. Their careers may be put on hold. They may have to take significant time away from work, which may or may not place their positions in jeopardy. They may have to move back home with their parents, which may involve having to move across the country. They often do not have financial resources (e.g. savings, 401(k)) to address the magnitude of cancer costs. While their peers are going through normal life steps (i.e. going to college, dating, or getting married and having children), young adults with cancer often isolate themselves and feel alone, thinking that their friends and family cannot understand what they are going through.

Anxiety and depression are not uncommon side effects of a cancer diagnosis. Chemotherapy can induce early menopause, a life and health change young women are not meant to experience for another 20 to 30 years. Early menopause impacts sexual libido and causes vaginal dryness. While in treatment and, potentially, for years to come, physical concerns like bone density and cardiac toxicity must be monitored. This could include taking preventative medication post-treatment (e.g. for osteoarthritis).

All of this impacts the young adult’s identity and life as he or she knew it. These side effects can last well past treatment when a young adult “looks fine” to the outside world while, “inside,” he or she is struggling emotionally, physically and existentially. They need and deserve support.

Celebrating its 20<sup>th</sup> year, the Young Survival Coalition (YSC) is the premier organization dedicated to the critical issues unique to young women diagnosed with breast cancer. YSC offers resources, connections and outreach so women feel supported, empowered and hopeful.

We offer a multitude of wonderful ways to connect and a wealth of resources. A young survivor can connect 1:1, in person and online (both in support group format and through social media). Our national Summit typically hosts 600 young survivors and their loved ones each year. Our educational materials are available for free to download or order in hard copy through our website. Our support and resources are there so that every young woman diagnosed with breast cancer knows that she is not alone at any stage and at any point in her journey. This includes resources for metastatic young survivors whose concerns and needs deserve attention and support.

YSC also supports Co-Survivors (e.g. spouse/partner, family member and friend). Co-Survivors may instinctively place their survivor's needs before their own. That can come at a cost; their health could be impacted as well. YSC offers support and resources to our Co-Survivor population.

We want to make sure no young adult and their co-survivors face breast cancer alone. YSC is here to help. Please reach out!

### **About the Author**

Jean Rowe is Associate Director of Support Services, Young Survival Coalition (YSC). She joined YSC in 2011 with a background in clinical oncology social work. She is a licensed clinical social worker, a certified oncology social worker and a certified journal therapist. Her focus includes the crafting, piloting and implementing of supportive and educational programming for young breast cancer survivors, co-survivors and health care providers. As a certified journal therapist, Jean crafted an original program addressing re-establishing intimacy after breast cancer as well as continuing education journal writing programs for mental health and nursing professionals regarding compassion, fatigue, and self-care. She holds a master of social work from the University of Georgia and a bachelor of arts from the University of South Carolina.

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# What Comes Next: How to Find the Right Therapist

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For the past several months, Real World Health Care has focused on the behavioral health issues that can impact people living with cancer, their caregivers and their loved ones. We've brought you insights from therapists, social workers and mental health professionals, and we've highlighted the numerous resources available from a variety of patient support organizations.

We've also shared information from our sponsor, the HealthWell Foundation, about its [Cancer-Related Behavioral Health Fund](#), which provides financial assistance to individuals with a diagnosis of cancer to help with cost-shares for covered services rendered by behavioral health providers.

As our series comes to its conclusion, we are pleased to help our readers “connect the dots” by highlighting recommendations from [Mental Health First Aid](#) on how to find a good therapist. The following article was originally published by Franziska Ross on August 31, 2018 and is reposted here by permission of the [National Council for Behavioral Health](#). [Click here](#) to view the original article.

Finding the right therapist can be a daunting task. This guide will walk you through the process, step-by-step.

## Work with Your Insurance

One of the biggest barriers to therapy is cost, so most people want to find a therapist who is covered by their insurance. A good place to start looking for therapists who take your insurance is your health care provider's website. Most provider websites have a “Find a Doctor” feature you can use to search for mental health clinicians near you, just like you would a physician. You can also select your health care provider on websites like [PsychologyToday.com](#).

## The Search – Things to Keep in Mind

Don't get bogged down in the different professional degrees that a therapist can have – Ph.D., Psy.D., LCSW, LCMHC, etc. Any therapist who is licensed in your state has gone through rigorous background checks and training.

Some people have a strong demographic preference – men vs. women, for example. Unfortunately, finding someone who meets your exact criteria can be difficult. The good news is that you can still develop positive and productive relationships with a therapist who does not entirely align with your original criteria.



Most therapists list their treatment methods. They might say, for example, that they have a psychodynamic or behavioral approach. If you're familiar with different approaches and you know what you're looking for, great! If not, don't worry. You can learn about the different general approaches online or wait to ask the therapist about their approach.

You might also want to take location into consideration. It's helpful, for example, to pick a therapist who works near your home, work or school. Doing so eases the stress of transportation, scheduling and time.

## **Picking Up the Phone**

Now comes the big (and often scary) step – making calls.

You have a list of possible therapists. It can be challenging to call a therapist without knowing them first. Some people find it helpful to make a list of talking points or a loose script to help guide the conversation. For example, you might start off with “Hi, my name is \_\_\_\_ and I’m looking for a therapist to help me work on \_\_\_\_.”

## **Asking Questions**

In your initial phone conversations, therapists expect and appreciate questions about their education, licensure, experience and approaches to care. Asking questions can give you a sense of the person's therapeutic style and if they could be a good fit. Here are some questions which you might want to ask: Where did you get your training? Do you have experience treating such-and-such issue or working with such-and-such population? Do you use evidence-based practices like cognitive behavioral therapy (CBT) or mindfulness? Do you take my insurance or have a sliding pay scale?

## **Availability – A Common Roadblock**

Keep in mind that you might not be able to schedule an appointment with the first person you call. You might discover that your insurance provider's records are outdated and some of the therapists listed no longer take your insurance, or maybe no one you initially reach is accepting new clients. It could take many calls before finding someone. Some people find it helpful to set up a schedule, a time to make and receive calls. When you leave messages, be sure to include your full name, call back number, times and dates that are best to reach you and your insurance information.

This is often a challenging and frustrating part of the search for a therapist, so it can be a good time to lean on those you are close with for support.

## **The First Session**

The first few sessions are a time to explore if the therapist is a good match. Therapy can be uncomfortable, especially in the beginning, so it's not unusual for the first few sessions to feel scary and awkward. However, an important sign if the therapist is a

good fit is if you feel they create a space of emotional safety and comfortable physical boundaries.

A sign that the therapist is not a good fit is if they cross your physical or emotional boundaries in any way. If there's something that would compromise your ability to have a good relationship with a therapist, don't ignore it. Instead, try to schedule an appointment with a different therapist. Seeing multiple people can feel like a lot of effort, but finding the right person is worth it.

Good therapy is based in a good relationship. A healthy part of therapy for many is having a conversation about the therapist-client relationship. If the relationship doesn't feel right, it's okay to tell your therapist how you feel about the dynamic and that you might need to see someone different. A good therapist will be open to that conversation and will support you through that decision.

## **Empower Yourself**

As a client it's important to empower yourself. Therapists have a code of ethics which they must follow. The [code of ethics for social workers](#) and the [code of ethics for psychologists](#) are both available online. These are good references to have in the case of any inappropriate behavior or if you think your therapist has crossed a boundary. You can also report any inappropriate behavior to your state licensing board.

## **When Therapy Isn't an Option**

For many reasons – family, location or money – therapy simply isn't an option for some people.

Unfortunately, many people still do not have access to insurance. In these cases, integrated care facilities like Certified Community Behavioral Health Centers (CCBHCs) and Federally Qualified Health Centers (FQHCs) are good options because they provide care regardless of an individual's ability to pay.

For those who do not have access to therapy but need help, hotlines are a great resource. There are many different [regional and national hotlines](#) available that provide support for different issues, including [suicide](#), [sexual assault](#) and [domestic violence](#). Trained advocates will support you through both critical and non-critical situations – you do not need to be in an immediate danger to call. While hotlines are not a substitute for counseling, they can be an important source of support.