

Maintaining Patient Connections with Online Support Groups





C OVID-19 has brought change for all of us, but for cancer patients and survivors that change has been particularly profound. Whether they are in active treatment or survivorship, people living with cancer often experience significant physical limitations, and this pandemic has put considerable restraints on aspects of all of our lives.

The accompanying loneliness that this isolation can bring has no easy remedy. Before COVID-19, many patients, survivors, and caregivers had the option of attending support groups that brought them into the company of other people also living with cancer. The effect that such groups can have on the lives of patients and their loved ones is often significant. Being able to communicate with others experiencing common challenges is a powerful coping tool.

Part of the hardship of COVID-19 is that the imperative to stay well by sheltering in place eliminates the option for group gatherings and other much-needed sources of peer support. As the pandemic swept the nation earlier this year, and as healthcare facilities subsequently closed their doors, support groups and services were among the first casualties. Patients accustomed to regularly coming together to share their challenges and triumphs were suddenly confined to their homes.

As with many other groups and organizations, some cancer programs and practices have reached out to their patients virtually to provide the encouragement they once enjoyed in face-to-face support groups. Since March 2020, Elizabeth Bornstein, MSSA, LCSW, OSW-C, APSH-C, an oncology clinical counselor at the Sarasota Memorial Cancer Institute in Florida, has helped the patients she once counseled in person transition to virtual sessions.

“My mission has been to meet and help people where they are,” says Bornstein. “Since March, Florida residents have had to hunker down at home, and that includes our cancer patients and their loved ones. So for them to be able to step out of their

Our groups are facilitated by a range of professionals: nurse navigators for networking and education groups, licensed mental health professionals for weekly support groups, and certified practitioners and instructors for the other groups.

isolation, even for just a little bit each week, and to feel a sense of connection to others going through similar situations, is so important.”

Bornstein spoke to *Oncology Issues* about how she was able to keep the lines of communication among patients open after her clinic’s doors closed.

Q. Tell us about Sarasota Memorial Cancer Institute.

A. Sarasota Memorial Health Care System is located in Sarasota, Fla. Founded in 1925, this 839-bed regional medical center is one of the largest public community health systems in the state. It has a comprehensive range of services, with specialized expertise in heart, vascular, cancer, orthopedic, and neuroscience services, as well as a network of outpatient centers. We also have urgent care centers, laboratories, diagnostic imaging, physician practices, skilled nursing, and rehabilitation programs. It is the only hospital in Sarasota County that provides obstetrical services, pediatrics, Level III neonatal intensive care, psychiatric services, and a Level II trauma center.



When it is completed in 2021, the Sarasota Memorial Cancer Institute oncology tower will serve as the heart of Sarasota Memorial Health Care's evolving cancer program. From the ground up, the oncology tower is designed to provide a patient-centered environment for services that cover the entire continuum of cancer care---from prevention, screening, and diagnosis to treatment, clinical trials, follow-up, survivorship care, and support.

In 2019 the Cancer Institute began a major expansion of its services with the groundbreaking of an oncology tower on the main campus and a radiation oncology center at a satellite campus. When all phases of the expansion are complete, the Cancer Institute will provide the full spectrum of patient-centered cancer services.

Q. What support groups do you provide?

A. About two years ago, we took responsibility for a range of cancer support and wellness programs that we had previously collaborated on in our community. We became responsible for 20 groups with 75 meetings happening each month. All groups are under the umbrella of our integrative cancer support and wellness services known as the Thrive Program.

All of these groups were ongoing prior to COVID-19. They are all outpatient and meet at different locations in our community.

People with cancer and their loved ones could attend based on what was most interesting, helpful, and convenient for them location-wise, and they had free access to all of them.

Q. What were your groups like before the coronavirus struck?

A. Of the 20 groups, some are cancer-specific monthly, weekly, and bi-weekly gatherings, and they include networking and education groups, support groups, arts-based groups, and others, such as meditation, yoga, tai chi, and qigong. They were happening at different locations until March, when we put the Thrive Program on hold because of COVID-19. We serve a community with a predominantly senior population and our groups are open to adults of all ages.

Our groups are facilitated by a range of professionals: nurse navigators for networking and education groups, licensed mental



Sarasota Memorial's Radiation Oncology Center is a 17,000-square-foot facility that offers two state-of-the-art linear accelerators for external beam radiation and an array of integrative care services to support holistic patient care.

health professionals for weekly support groups, and certified practitioners and instructors for the other groups. I facilitate a weekly patient support group and a weekly patient and caregiver support group with a nurse navigator, and a colleague facilitates a weekly caregiver support group. Our goal has been to provide these groups in person for our local community members who can benefit from these connections with one another close to their homes.

Q. What happened to your groups once social distancing became necessary?

A. Out of an abundance of caution and due to social distancing guidelines, we put our groups on hold in the beginning of March at the direction of our leadership. Knowing how important these groups are for connection and support, I was very concerned about abruptly ending them. I reached out to each of the group members by phone, just checking in on how they were doing in the midst of COVID-19 and asking how they were going about their day-to-day lives.

My colleague who facilitates the caregiver group was doing the same. In conversations with our Thrive coordinator, I expressed concerns about the level of isolation our patients and their loved ones were experiencing with their groups being on hold. I offered to pilot the virtual groups, and the decision was made to move forward. We knew it was the right thing to do.

Since we already knew the people coming to the groups every week and we had already completed their registration forms, we felt comfortable moving ahead. We consulted with our legal department and were told our existing registration forms were sufficient. We decided we would wait before adding additional group members until we had a comfort level with the virtual process. We informed our group participants about our move to virtual groups and gave them instructions and practice options. I began conducting support groups virtually in the last week of March, and my colleague began her group in the beginning of April.



The lobby of Sarasota Memorial's Radiation Oncology Center.

Q. Which platform do you use to host your virtual groups?

A. Our health system had already started using a Cisco platform called the Meeting App. It is simple and easy to use and had already been implemented in multiple areas of our health system, including Outpatient Behavioral Health and Oncology Counseling programs. It made logical sense to use a platform that was already proving successful in other areas. We were given training and written guidelines on how to arrange groups and invite participants to them. I learned to manage access to the groups, and I created a participant user guide to share with our group members.

Q. Did you encounter any technology or learning roadblocks?

A. The biggest challenge was that many participants had never used video conferencing like this before, so they didn't really know the etiquette or what steps to take to join.

I shared with participants the instructions that we created, and I offered initial and ongoing support as needed, including

practice time to master the process of logging on. I gave participants a backup plan if something went awry with their video, so they could always call in on the phone. In one of our weekly groups, the majority of people were not initially comfortable with using the video, so we opted to use audio only for that group.

We decided to use the call-in option as a backup, as with technology connectivity can always go awry. There is a high level of uncertainty with COVID-19, so we didn't want the technology to cause undue stress for our participants. We provided reassurance and reminded the participants that the goal is to stick together no matter what challenges come our way.

Q. Is it more challenging serving patients in this space?

A. Access to and understanding of technology is a barrier for groups like ours and for people in general who want to stay connected with their family and loved ones during this time. It can be overwhelming and anxiety-provoking for people not accustomed to using this technology.

I wish there were an easier way for the mostly senior elders and people who are underserved in our community to access this technology. When people don't have access to tools to connect with one another, it is so isolating. When people do have the right tools and assistance, they are able to access the technology and join groups. Family members have come through in getting participants computers or tablets, so they can get involved in the video component of the groups. Even if we are only able to have participants join groups by audio, it is quite meaningful.

In our groups, we celebrate when we are able to connect and maintain our connections in any way possible. Whether via audio or video, we have proven that our patients can stay connected to one another. It is working so well, we've decided to add new participants as they express interest. We are completing the registration forms with them ahead of time by email or postal service and then training these new participants on how to join the groups when they meet.

As we well know, cancer doesn't go away because of a pandemic. Our group participants have still had to undergo tests, procedures, and treatments, as well as make difficult decisions, for example, about end of life. COVID-19 has certainly made living with cancer more challenging. Virtually, we've shared our sorrows and grief and have still managed to find a way for warmth, compassion, and connection to shine through.

Q. Do you have concerns about patient privacy?

A. Privacy is definitely a concern. That's one reason we were reluctant to explore any kind of virtual group previously. We can't really know who is in each person's home space. We can't control who is listening. We established ground rules and review them as part of our weekly support groups. We emphasize that privacy is of the utmost importance, and what is shared in the group stays in the group. We also remind participants each week that even though we're sitting in our offices, or our living rooms, or our kitchens, these are still support groups. This is an opportunity for each person to share openly, and our privacy depends on an honor code. We emphasize that to make sure people really understand.

Our health system selected the Cisco application in part because it is HIPAA compliant. Even though regulations are being relaxed right now during COVID-19, we really wanted to start this online effort on the right footing and have everything that we need in place for the long term. So we picked that platform intentionally. We're also using the existing registration form for entrance into our Thrive Program that is required for anyone participating in any of our groups.

Q. What do you think the future holds for your program's support groups?

A. If we had a magic wand, we would go back to the way it was before COVID-19. We hope the future can bring some level of normalcy soon. Originally, when we put our groups on hold, we anticipated that they would continue online until mid-April, when we would return to the office, but things have changed quite a

bit since then. There's a lot of uncertainty we hadn't anticipated, so we're taking things as we go.

Q. Do you plan to expand these groups beyond their current membership?

A. Yes. We are in the process of bringing four of our monthly networking and education groups online. One is currently happening. We've also had interest in creating new weekly support groups, although we haven't embarked on that yet.

Virtual groups offer advantages particularly for people who are reluctant to leave their homes or who aren't feeling well enough to travel. Now that we've been offering our support groups online, I've heard interest from people all over our service area, some of whom have not previously attended in-person groups. Before, there was not enough participation to justify starting disease-specific weekly support groups, but now it seems there may be enough interest, particularly since people will not need to travel to their groups. Our Thrive Program is considering the potential options.

Q. Are there any lessons learned from your transition to virtual support groups that others may benefit from?

A. There are challenges with moving in-person groups to virtual groups in the way of completing screenings and registrations, maintaining privacy, addressing compliance concerns, and helping participants adjust to the necessary technology. Yet the benefits certainly outweigh the challenges, and it is well worth the effort. Virtual groups clearly foster and sustain human connection. As the uncertainty of the pandemic continues, our participants say that their virtual groups have been a lifeline, and they are grateful for them. We are committed to caring for our patients and their loved ones and continuing to make the groups happen.

Q. Any parting thoughts?

A. For cancer programs around the country considering moving their support groups online, I would say even with the unknowns and figuring it out as you go, in light of the times, it is critical to be able to offer support virtually. We've kept it simple, and we've found it's doable. Make it manageable by starting out small with a group or two. You can always expand once your comfort level grows.

I encourage people to open their minds, find the resources, and make the time to figure out how best to offer something that will truly reach people in need. There are a lot of people with cancer in need of support and connection, especially now. COVID-19 isn't going away any time soon. Our patients and loved ones are depending on us to help them face the uncertainty of their cancer in the midst of this pandemic. Doing so together is the antidote for the understandable feeling of isolation while hunkering down at home. 

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