Young Adult Patients Tap into Long-Distance Support

BY LAURA MELTON, PHD, ABPP

Having shown to reduce distress in patients with cancer, support groups are the backbone of supportive oncology care.[1,2] However, though support groups can be a useful coping mechanism for patients, the effectiveness of such groups tends to be limited by distance and high attrition rates. Not surprising, when arriving at the University of Colorado Cancer Center in 2014, I noticed that attendance at support groups was low, a trend reflected in current literature.[3] In fact, many support groups at the cancer center were being canceled due to low turnout. In response, I partnered with my colleague, Benjamin Brewer, PsyD, to address the issue.

Getting Started

Dr. Brewer and I proposed creating an online video support group to enable patients with cancer who would otherwise have difficulty attending such groups to participate virtually. Many patients being treated at the University of Colorado Cancer Center are prevented from physically attending support groups by a variety of obstacles, including living long distances from the center, having transportation issues, being unable to take time away from work or family, and suffering from side effects that prevent them from traveling.

Our first hurdle in creating a virtual support group was to establish a foundation of reliable technology. Without dedicated tech support in our cancer center, we knew that we had to find an easy, user-friendly approach. The hospital's information tech-

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nology group suggested that we use Zoom as our video conferencing platform because it was secure, Health Insurance Portability and Accountability Act compliant, low-cost, and easy to use. Because Dr. Brewer and I were unfamiliar with Zoom, we recruited colleagues to test the software to ensure that we had appropriate devices and bandwidth, to see what Zoom's visual aesthetic looked like, and to become familiar with various software functions. We also tested the invitation function and the ease of accessing meetings.

Securing Remote Access

Because we did not know which devices support group participants would use to access Zoom, or the reliability of participants' internet connections, we could not be certain whether individual participants would be able to reliably access the group. There was also the possibility that participants may not possess the necessary hardware at all—though data show smartphone ownership rising to 68 percent of adults in the United States in 2015 (up from percent 35 percent in 2011), that still left a substantial gap of 32 percent of the population without smartphones.[4] A grant from the Colorado Cancer Fund enabled us to remedy this problem and purchase tablets—on which we installed Zoom—for each pilot participant to use to access the group.

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Our second access concern was the reliability and speed of participants' internet access, given Colorado's geographic diversity. Colorado has few dense metro areas, with 47 of Colorado's 64 counties designated as rural.[5] Of the 47 rural counties, 23 are further designated as frontier, meaning that they are sparsely populated rural areas isolated from population centers and services, with a population density of six or fewer person per square mile.[5] Even if participants had online access, unreliable internet service could result in poor connections. Paused or interrupted communications would be particularly bothersome in the context of the emotional exchanges that can take place in support groups. We therefore decided to screen potential participants for the required broadband access by having them complete internet speed tests from their specific locations.

Our next challenge was how to secure the privacy of our participants in a virtual space. In traditional face-to-face support groups, facilitators can control the environment, adjusting the arrangement of the room and positioning chairs so that participants can be assured of the privacy of their communications. Allowing participants to choose their environment introduced a new variable in that other people may be present without being seen, meaning that group members could be overheard. To avoid this possibility, we encouraged group members to use headphones equipped with microphones, which we provided with each tablet.

Doing so would help better preserve confidentiality by avoiding the possibility of overheard conversations and encouraging participants to be strategic in choosing their locations during group sessions. Headphones would also decrease background noise and thus aid in maintaining participants' attention.

A New Dynamic

We anticipated that switching from face-to-face to a virtual video platform would change the dynamic of the group. For example, support group facilitators are used to observing participants' body language and managing distractions that can interrupt the group if not quickly addressed. Our facilitators understood that a video chat group would only allow them to observe participants from the shoulders or neck up and that they might subsequently miss subtle cues. Facilitators would now need to gauge facial expressions in a grid of the participants' faces. (Zoom's video interface enables a video presentation in which nine participants can see one another simultaneously in a 3×3 grid.) For that reason, we limited the group to eight participants so that everyone (eight participants and two facilitators sharing a screen) could be seen at the same time (see Figure 1, right).

Group facilitators are also responsible for monitoring and responding to high-risk statements from individual group members. For example, facilitators engage participants in personal conversations after a group discussion if anyone expresses suicidal or homicidal ideation. The facilitator would likely discuss imminent risk and make a follow-up plan for personal support. Additionally, facilitators often ask participants who are disruptive or found to not be a good fit for a group to stay after the group to privately discuss behavioral expectations or more appropriate referrals.

Being unable to physically remain after an online group to have crucial conversations, we needed an alternative plan to help keep participants safe. Our solution was to require participants to provide phone numbers and home addresses so that we were able to follow up after video sessions if we had concerns about personal harm or felt the need to have a private conversation. Having this information also gave us a way to contact local authorities if a participant expressed imminent danger to self or others.

Personal connections can form among participants when they are outside of the support group. For example, it is common for participants to exchange contact information, grab refreshments with other group members, and/or meet up for social events. With Zoom, when the host of the meeting ends a session, it disconnects all participants without giving them the option to stay afterward and converse. Our group members missed these opportunities to make connections with one another, so they asked facilitators to use group time to exchange personal contact information. Many did keep in touch with one another and even met in person after the pilot program ended.

The Pilot Program

Though we considered many specific patient populations for our pilot, one group was particularly attractive. Young adults

Figure 1. Visual Representation of Video Feed Screen

with cancer are considered an "orphaned population" in that they experience elevated levels of psychological distress, yet remain largely overlooked by cancer control, prevention, and quality-of-life investigations in the United States.[6-9] The fact that young adults have a higher rate of smartphone and tablet ownership than other demographic groups and that young adults who have been diagnosed with cancer are already familiar with sharing and expressing themselves online suggested to us that this group may markedly profit from virtual health services.[4,10] For this reason, we targeted individuals ages 18-40 for the pilot program.

The University of Colorado Cancer Center has a large catchment area, frequently drawing patients for care into the Denver metro area from surrounding states. To be legally authorized to provide psychology and social work services, licensing laws require providers to have professional jurisdiction in the state in which a patient is located when the services are rendered. For that reason, group participants had to be physically present in Colorado during group sessions. Thus, we limited ourselves to recruiting and enrolling only Colorado residents.

The eight participants enrolled in our virtual support group resided in eight different counties in Colorado, allowing us to reach a large, diverse geographic region (see Table 1, page 18). The fact that the participant who had the longest drive time to the cancer center did not live the greatest number of miles away is indicative of the nature of the mountain driving and rural roads that can impact ease of transportation in Colorado. Less predictable but not uncommon are delays due to wildlife crossings, falling rocks, mud slides, avalanches, snowstorms, and other adverse weather events.

We screened potential participants over the phone, asking them questions about their comfort using tablets and having them perform high-speed internet access tests at home. All accepted group members were sent Wi-Fi-enabled tablets equipped with Zoom software. Headphones with built-in microphones were also provided. Participants were sent welcome emails from the group facilitators, with directions on how to join the support group. Additional emails reminded participants of each upcoming session.

The group met virtually for six consecutive weeks, with each session lasting 90 minutes. As participants joined each session, they were assigned a space in the 3 × 3 screen layout so that everyone could see one another (Figure 1, page 17). At the first group meeting, participants were prompted to generate a list of topics they wanted to cover over the course of the six-week pilot program. An oncology social worker and an oncology psychologist facilitated each session, which consisted of a member check-in followed by a discussion of the topics suggested by support group participants.

Table 1. Participant Geographic Information from Pilot Program

County of resident	Arapahoe, Boulder, Douglas, Eagle, El Paso, Jefferson, Larimer, Las Animas
Distance from participant's home to cancer center	Average: 148 miles Range: 25 miles to 406 miles
Drive time from participant's home to cancer center (without traffic)	Average: 2 hours and 56 minutes Range: 38 minutes to 6 hours and 18 minutes

Table 2. Virtual Support Group Participation

Number of Weeks (Out of 6)	Number of Participants (Out of 8)
1 week	8 participants present
2 weeks	6 participants present
3 weeks	7 participants present

Lessons Learned

Turnout for the virtual support group was high for each of the six sessions. No participants dropped out of the group, and few missed any session (see Table 2, below). When we asked for feedback, participants told us that they liked the virtual support group and felt comfortable participating in it.[11] Our experience was that meeting virtually did not prevent group members from bonding with one another. Further, various participants exchanged contact information and met one another in person.

We found that the virtual aspect of the group increased access for this population.[11] Participants shared that their often poor physical health—which could result in immunosuppression, feeling ill, or being hospitalized—and the distance to the cancer center would likely have prevented them from participating in the support group in person.[11]

There were some inevitable drawbacks to meeting virtually rather than in person. At times, participants were distracted. Family members, pets, and electronics could vie for participants' attention, and it was evident from their expressions when someone ceased concentrating on the group. Group facilitators also had to adapt to a virtual meeting space. They said that facilitating a virtual group was more difficult than doing so in person, where body language was easier to read through physical positioning, interpersonal spacing, and nonverbal communication.[12] Group facilitators also noted that they could get distracted at times by seeing themselves on the screen, causing a sense of self-consciousness that is not present in a face-to-face group.[12]

On the positive side, facilitators shared that obtaining large meeting rooms and cleaning up afterward were no longer necessary.[12] Facilitators were also happy with the participants' consistent attendance and the opportunity to provide needed services to vulnerable individuals located in geographically remote areas.[12] Additional detailed results about the group were recently published in the journal *Palliative and Supportive Care*.[11]

Additional Discussion

Our pilot offers a unique approach to oncology support groups. Though many such groups are open (people can start or stop at any time) and ongoing (they are offered indefinitely), we started with a small, closed, screened group of patients and provided them the tools they would need to participate in a six-week program.

The success of the virtual support group program led us to adapt it to meet the needs of other patient groups. We currently offer multiple virtual support groups using Zoom. Though one group is entirely virtual, others are in-person/virtual hybrids that offer participants the option of attending sessions either remotely or in person. Many participants tell us that they would be unable to participate in their support groups if they did not have the option to do so virtually. For patients who do not have access to the technology that would allow them to participate in support groups virtually, Zoom offers the option to call in via phone. This audio-only option has enabled us to offer support groups to an even larger number of patients.

Much of our relatively slow adoption of virtual support groups comes from our facilitators' hesitation to embrace this new meeting platform. Facilitators cite being unfamiliar with conducting virtual groups, feeling apprehensive of using new technologies, and feeling unable to read nonverbal cues as reasons for their hesitancy to lead virtual support groups.

Though it is inevitable that some subtle communications will be lost in a virtual support group, our pilot has demonstrated that group connections can be made online, and we can effectively bring this service to patients who may otherwise be unable to benefit from it. For cancer programs interested in launching a similar virtual support group, we offer these tips:

- Know your state's jurisdiction and licensing laws. Depending on your profession and the states in which your facilitators are licensed, the laws governing telemedicine can differ widely.
- Health insurance billing is complicated. Laws about insurance coverage for telemedicine are ever-changing and are often regulated at the state level, further complicating national efforts to make available virtual healthcare offerings. One option is to start with a non-billable virtual support group. A free support group can be offered remotely without having to deal with the rules of insurance reimbursement.
- Select a platform that is easy to use for both facilitators and the participants. Facilitators should practice with colleagues until they feel comfortable with the platform before introducing it to patients.
- Anticipate and prepare for what could go wrong and make contingency plans. For example, we wanted the ability to respond to patients who express suicidal or homicidal ideation during a session. To counter this risk, we obtained the home addresses and telephone numbers of all participants. Decide how best to respond to unanticipated risks by having a plan in place to address them remotely.
- Take the plunge. You might not feel fully ready, and you may never feel that way. But if having a larger reach, improving access, and decreasing health disparities outweigh your discomfort, take the steps to adopt virtual support groups in your cancer program. OI

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