

Increasing access to care for young adults with cancer: Results of a quality-improvement project using a novel telemedicine approach to supportive group psychotherapy*

LAURA MELTON, PH.D., A.B.P.P.,¹ BENJAMIN BREWER, PSY.D.,² ELISSA KOLVA, PH.D.,¹
TANISHA JOSHI, PH.D.,² AND MICHELLE BUNCH, L.C.S.W.³

¹Department of Medicine, Division of Medical Oncology, University of Colorado Anschutz Medical Campus, Aurora, Colorado

²Department of Medicine, Division of Hematology, University of Colorado Anschutz Medical Campus, Aurora, Colorado

³University of Colorado Hospital, Aurora, Colorado

(RECEIVED March 21, 2016; ACCEPTED June 25, 2016)

ABSTRACT

Objective: Young adults with cancer experience high levels of psychological distress. Group interventions for cancer patients have been effective in reducing levels of psychological distress but suffer from high levels of attrition and serve a limited geographic area. In a quality-improvement project, we converted an existing in-person support group to a telemedicine format in the hopes of improving attendance and reducing geographic disparities in access to care.

Method: Eight young adults (18–40 years) with cancer were recruited from across Colorado. Participants received a tablet equipped with Wi-Fi and downloaded an HIPAA-compliant video-conferencing application. Participants attended six weekly supportive psychotherapy sessions.

Results: Participants found the group to be beneficial: the technology worked, they enjoyed the group format, and they would recommend it to others. The novel treatment interface allowed for low attrition rates due to the flexibility of a patient's location during the intervention. It allowed for provision of services to a geographically diverse population of medically ill young adults, as participants lived an average of 148 miles from the cancer center (range = 25–406 miles).

Significance of results: Internet-based mental health care is an area of growing interest for providers, but few studies have evaluated its efficacy in patients with cancer, and even fewer in young adults with cancer. Incorporating technological advances into clinical practice will increase access to care, reduce geographic health disparities, and provide more consistent services.

KEYWORDS: Young adults, Cancer, Telemedicine, Internet-based interventions, Support group

INTRODUCTION

Adolescents and young adults who have been diagnosed with cancer experience the highest levels of

psychological distress of any age group (Lebel et al., 2013; Sansom-Daly & Wakefield, 2013). When compared to pediatric and adult oncology populations, young adults aged 18–35 (Zebrack et al., 2006) have been on the periphery regarding cancer control, prevention, and quality-of-life research in the United States (Wu et al., 2005) and have been identified as an “orphaned population” (Fernandez & Barr, 2006). A diagnosis of cancer is particularly disruptive to the development of young adults as it can interfere with a critical developmental period

*This is a report on an innovative quality-improvement effort to utilize telemedicine technology to increase access to support groups for young adults with cancer.

Address correspondence and reprint requests to: Laura Melton, Department of Medicine, Division of Medical Oncology, University of Colorado Anschutz Medical Campus, MS 8117, 12801 East 17th Avenue, Aurora, Colorado 80045. E-mail: Laura.Melton@ucdenver.edu.

focused on identity, relationships, and educational and occupational development (Kim & Gillham, 2013). This disruption can have longlasting effects on psychosocial functioning (Zeltzer, 1993). Serious illness is very rare in this age group, and peer support is often lacking. Many young adult patients report that their previously supportive group of friends have difficulty understanding and relating to their experience with cancer.

The literature suggests that supportive group interventions can reduce distress in cancer patients (Breitbart et al., 2015; Spiegel & Classen, 2000), but such interventions suffer from high levels of attrition, often due to the poor physical health of patients (Applebaum et al., 2012). Factors that contribute to attrition are particularly relevant in such large, geographically diverse areas as Colorado (U.S. Census Bureau, 2010), in which 40–60% of residents are medically disenfranchised (Universal Service Administrative Company, 2013). Consequently, young adults with cancer can be further isolated from those who share a similar situation and from treatment centers that can provide targeted psychological interventions designed to reduce cancer-related distress and improve quality of life. Internet-based interventions may help minimize the impact of barriers to participation in support groups.

Telehealth is increasingly popular as a platform for cancer prevention (e.g., Carlson et al., 2012; Sabesan et al., 2015), as well as for monitoring and treating the physical symptoms and side effects of cancer and its treatment (Bouma et al., 2015; Breen et al., 2015; Haozous et al., 2012). Within psychosocial oncology, telemedicine is being utilized to respond to positive distress screens (Mayer & Damore-Petingola, 2015) and provide support for the psychosocial symptoms of cancer (Bouma et al., 2015; Shaw et al., 2013; Stephen et al., 2013). Telemedicine interventions are generally gaining support within the broader mental health community as well (Hilty et al., 2013).

From 2011 to 2015, smartphone ownership rates have risen from 35 to 68% of adults in the United States (Anderson, 2015). Rates of smartphone ownership show a substantial gap based on age, with 86% in the 18–29 age range, 83% in the 30–49 range, and then a substantial drop to 58% in the 50–64 range and 30% in the 65+ range (Anderson, 2015). Similarly, tablet use has seen a dramatic recent increase in ownership, with a gain from 4 to 45% of U.S. adults owning a tablet from 2010 to 2015 (Anderson, 2015). Tablet use has a similar trend in higher ownership with younger adults: 50% among 18–29 year olds, 57% among 30–49 year olds, 37% among 50–64 year olds, and 32% in the 65+ age group (Anderson, 2015).

Young adults have high rates of ownership of smartphones and tablets (Anderson, 2015), and young adults with cancer often use the internet to express themselves and share experiences (Kim &

Gillham, 2013). This predisposition to having internet-accessible devices and seeking support online suggests that young adults may particularly benefit from telemedicine interventions. We integrated technology into an existing in-person young adult cancer group in order to address common barriers to attending the group, such as transportation concerns, conflicting work schedules, education, family responsibilities, health concerns and hospitalization.

METHODS

Participants

Cancer patients were recruited across the state of Colorado through hospitals and cancer centers. Personal emails were sent to known oncology teams, and flyers were sent to our hospital's email list of patients (who had requested to receive information) and staff (internal and external). This method of recruitment mirrors the recruitment methods we use for our in-person groups, as we are the only comprehensive cancer center in Colorado and advertise our support services throughout the state, as we frequently have people attend our support groups who do not receive their treatment at our center. Our group participants in the present study were all Colorado residents, English-speaking, between the ages of 18 and 40 years, and had a cancer diagnosis. All participants had access to wireless internet and were comfortable using a tablet or computer. Demographic information for the eight participants can be found in Table 1: age, gender, race/ethnicity, education, marital status, cancer type, and current cancer treatment. Additional demographic data (e.g., time since diagnosis, prior history of participation in psychosocial services) were not collected. The first eight eligible participants were enrolled in the group.

Measures

Participants provided basic demographic data as part of the initial screening process to determine group eligibility. Following the final group, participants completed an online questionnaire evaluating the video platform and their satisfaction with the group. They were also encouraged to provide typed qualitative feedback. Seven of the eight group members completed the questionnaire.

Procedure

As this was a program-development endeavor, institutional review board (IRB) approval was not sought, and this project was not required to go through the IRB because this research was an attempt to develop and expand supportive care services for patients at

Table 1. Participant demographics (N = 8)

Age (in years)
Range: 18–40
Average: 30.1
Gender
Female: 50% (n = 4)
Male: 50% (n = 4)
Race/ethnicity
Hispanic: 25% (n = 2)
Caucasian: 75% (n = 6)
Education completed
High school: 12.5% (n = 1)
Some college: 87.5% (n = 7)
Relationship status
Single: 62.5% (n = 5)
Married: 12.5% (n = 1)
Divorced: 12.5% (n = 1)
Cancer type
Hematological malignancy: 87.5% (n = 7)
Soft tissue cancer: 12.5% (n = 1)
Current cancer treatment
Active cancer treatment: 37.5% (n = 3)
Graft-versus-host disease treatment: 25% (n = 2)
Not currently receiving treatment: 37.5% (n = 3)

our cancer center. Patients who participated in the group were not compensated monetarily. Given the nature of the project, we wanted all participants to have the same technology available to them as we attempted this telemedicine group format. Participants received a tablet with wireless capability and instructions to download a HIPAA-compliant video-conferencing application. They attended six weekly 90-minute support group sessions facilitated by two licensed oncology/mental health professionals (one psychologist, one social worker). Groups consisted of initial check-ins with members and discussion of topics of interest that were generated by group members during the initial session. These included connecting with peers and isolation in the cancer process, building interpersonal relationships while battling cancer, developing coping skills specifically to address fear of recurrence and uncertainty, and balancing hopefulness with realism in light of having a potentially terminal diagnosis. Participants received a reminder email one or two days before each session.

RESULTS

Attendance

All participants remained in the group for the entirety of the intervention, with at least six of the eight participants joining each session (see Table 2). Reasons for absences included delayed delivery of the tablet

Table 2. Group attendance

	Present	Absent
Week 1	6	2
Week 2	8	0
Week 3	7	1
Week 4	6	2
Week 5	7	1
Week 6	7	1

(1), planned engagements (2), forgetting (2), a medical appointment (1), and a medical emergency (1).

Distance and Travel

Participants resided in eight different counties in Colorado. Members were able to participate in the group from an average distance of 148 miles (range = 25–406 miles), or nearly three hours away from the cancer center (see Table 3). Participants provided written feedback about the convenience of the online group:

- “I live far from Denver, so it made it much more convenient.”
- “Travel time. I live two hours from Denver. It would not have been feasible for me to drive there every week.”
- “Extremely convenient. Not using gas.”
- “People from all over [Colorado] could join. We could spend more time talking and less time traveling.”

A severe weather event that occurred close to the cancer center shortly before one of the meetings did not deter people from attending the group, since they did not need to travel.

Table 3. Distance between cancer center and participant homes

	Roundtrip distance: home to cancer center (miles)	Roundtrip drive time without traffic: home to cancer center
Participant 1	274	6 hours, 18 minutes
Participant 2	177	3 hours, 36 minutes
Participant 3	46	1 hour, 0 minutes
Participant 4	35	1 hour, 14 minutes
Participant 5	25	0 hours, 38 minutes
Participant 6	64	1 hour, 42 minutes
Participant 7	406	6 hours, 8 minutes
Participant 8	155	2 hours, 52 minutes
Average	148	2 hours, 56 minutes

Participant Health

Hospitalization is a major stressor in this population and a common cause of attrition in traditional groups. The flexibility of our group allowed young adults in active treatment to participate even while neutropenic and hospitalized, retaining the support of the group during this difficult event. One patient was hospitalized for her cancer the second week of group. In a traditional in-person group, she would not have been able to participate, but she brought her tablet to the hospital and joined in the group from her hospital bed. As a few participants noted,

- “I was neutropenic most of the time, so being in public wasn’t much of an option.”
- “Immunocompromised people could participate.”
- “Convenience of being able to participate with low blood counts and not having to drive anywhere.”

Comfort with the Technology and the Group

Table 4 illustrates participant responses to questions evaluating the group. Group members reported that they were comfortable using the technology. All participants who completed the follow-up questionnaire evaluating the group agreed that the technology worked well and that they felt comfortable using the video call. Similarly, they reported that the group worked well online, was practical and convenient,

and that none would have preferred to attend an in-person group. They unanimously reported feeling an increased sense of connection to others and satisfaction with the group process, and noted that they would recommend the group to others. As a few participants reported,

- “I thought it was great to be able to talk to others my age that can relate. It’s difficult to find people that truly understand the hardships of cancer at a young age.”
- “It was great to meet and interact with people that would otherwise have difficulty getting together.”
- “I wish I could have participated in something like this when I was going through treatment. It is important to know you are not alone as a young person with a rare cancer and that others have survived and [so] understand what you have experienced.”

DISCUSSION

Despite their benefit, sustaining in-person support groups for young adults with cancer can be difficult. Our group was successful in introducing a novel platform for a support group for young adults with cancer. The modern format increased access to care across a geographically diverse population, reducing health disparities between rural and urban communities. Cancer patients who are sick may be the ones who

Table 4. Group evaluation survey results

	Totally agree	Agree a little	Mixed feelings	Disagree a little	Totally disagree
The tablet and technology worked well	<i>n</i> = 7 (100%)				
I felt comfortable using the video call for the group	<i>n</i> = 7 (100%)				
I think this group worked well online	<i>n</i> = 7 (100%)				
I would have preferred this group to be held in-person				<i>n</i> = 2 (29%)	<i>n</i> = 5 (71%)
I found the technology and format of the group to be acceptable	<i>n</i> = 7 (100%)				
I found the technology and format of the group to be feasible and practical for my life	<i>n</i> = 7 (100%)				
It was more convenient for me to participate in the group online than it would have been for me to drive to an in-person group	<i>n</i> = 7 (100%)				
I feel satisfied with the group	<i>n</i> = 7 (100%)				
I would recommend this group to others	<i>n</i> = 7 (100%)				

need the most support. Our format allowed people to attend the group and receive support even when they were immunocompromised, sick, or hospitalized. As this was not a research project but a quality-improvement one, its results are nongeneralizable. Nonetheless, the enthusiasm for the group, low attrition rate, and high member satisfaction all indicate the need for further formal investigation.

DISCLOSURES

None of the authors have any conflicts of interest to declare. We have full control of all primary data and agree to allow the journal to review the data if requested.

ACKNOWLEDGMENTS

Funding for this project was provided by a grant from the Colorado Cancer Fund.

REFERENCES

- Anderson, M. (2015). *Technology device ownership: 2015*. Pew Research Center. Available from <http://www.pewinternet.org/2015/10/29/technology-device-ownership-2015>.
- Applebaum, A.J., Lichtenthal, W.G., Pessin, H.A., et al. (2012). Factors associated with attrition from a randomized controlled trial of meaning-centered group psychotherapy for patients with advanced cancer. *Psycho-Oncology*, 21(11), 1195–1204. Epub ahead of print Jul 12, 2011.
- Bouma, G., Admiraal, J.M., de Vries, E.G., et al. (2015). Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: A literature analysis. *Critical Reviews in Oncology/Hematology*, 95(1), 26–37. Epub ahead of print Jan 31.
- Breen, S., Ritchie, D., Schofield, P., et al. (2015). The Patient Remote Intervention and Symptom Management System (PRISMS): A telehealth-mediated intervention enabling real-time monitoring of chemotherapy side-effects in patients with haematological malignancies. Study protocol for a randomised controlled trial. *Trials*, 16(1), 472.
- Breitbart, W., Rosenfeld, B., Pessin, H., et al. (2015). Meaning-centered group psychotherapy: An effective intervention for improving psychological well-being in patients with advanced cancer. *Journal of Clinical Oncology*, 33(7), 749–754. Epub ahead of print Feb 2.
- Carlson, L.E., Lounsberry, J.J., Maciejewski, O., et al. (2012). Telehealth-delivered group smoking cessation for rural and urban participants: Feasibility and cessation rates. *Addictive Behaviors*, 37(1), 108–114. Epub ahead of print Sep 16, 2011.
- Fernandez, C.V. & Barr, R.D. (2006). Adolescents and young adults with cancer: An orphaned population. *Paediatrics & Child Health*, 11, 103–106.
- Haozous, E., Doorenbos, A.Z., Demiris, G., et al. (2012). Role of telehealth/videoconferencing in managing cancer pain in rural American Indian communities. *Psycho-Oncology*, 21(2), 219–223. Epub ahead of print Dec 22, 2010.
- Hilty, D.M., Ferrer, D.C., Parish, M.B., et al. (2013). The effectiveness of telemental health: A 2013 review. *Telemedicine Journal and E-Health*, 19(6), 444–454.
- Kim, B. & Gillham, D.M. (2013). The experience of young adult cancer patients described through online narratives. *Cancer Nursing*, 36(5), 377–384.
- Lebel, S., Beattie, S., Ares, I., et al. (2013). Young and worried: Age and fear of recurrence in breast cancer survivors. *Health Psychology*, 32(6), 695–705. Epub ahead of print Oct 22, 2012.
- Mayer, C. & Damore-Petingola, S. (2015). Using telehealth to respond to distress in rural and remote chemotherapy clinics. In *Handbook of oncology social work: Psychosocial care for people with cancer*. C.E. Christ et al. (eds.), pp. 155–162. Oxford: Oxford University Press.
- Sabesan, S., Kelly, J., Budden, L., et al. (2015). Telehealth: A new opportunity to discuss smoking cessation with indigenous cancer patients and their families. *Psycho-Oncology*, 24(10), 1324–1326. Epub ahead of print.
- Sansom-Daly, U.M. & Wakefield, C.E. (2013). Distress and adjustment among adolescents and young adults with cancer: An empirical and conceptual review. *Translational Pediatrics*, 2(4), 167–197.
- Shaw, J., Young, J., Butow, P., et al. (2013). Delivery of telephone-based supportive care to people with cancer: An analysis of cancer helpline operator and cancer nurse communication. *Patient Education and Counseling*, 93(3), 444–450. Epub ahead of print Aug 1.
- Spiegel, D. & Classen, C. (2000). *Group therapy for cancer patients: A research-based handbook of psychosocial care*. New York: Basic Books.
- Stephen, J., Rojubally, A., MacGregor, K., et al. (2013). Evaluation of CancerChatCanada: A program of online support for Canadians affected by cancer. *Current Oncology*, 20(1), 39–47.
- Universal Service Administrative Company (2013). *Network plan: Colorado Telehealth Network (CTN) as per para. 241 of the HCF order*. Available from http://usac.org/_res/documents/.
- U.S. Census Bureau (2010). *Guide to 2010 Census State and Local Geography—Colorado*. Available from http://www.census.gov/geo/reference/guidestloc/st08_co.html.
- Wu, X.C., Groves, F.D., McLaughlin, C.C., et al. (2005). Cancer incidence patterns among adolescents and young adults in the United States. *Cancer Causes & Control*, 16(3), 309–320.
- Zebrack, B., Bleyer, A., Albritton, K., et al. (2006). Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer*, 107(12), 2915–2923.
- Zeltzer, L.K. (1993). Cancer in adolescents and young adults: Psychosocial aspects. Long-term survivors. *Cancer*, 71(Suppl. 10), 3463–3468.