

Journal of Pediatric Oncology Nursing

<http://jpo.sagepub.com/>

The Teen Impact Experience: A Webcast Pilot Project for Teens With Cancer and Blood Diseases

Betty Gonzalez-Morkos, Octavio Zavala, Marcio Malogolowkin and Aura Kuperberg

Journal of Pediatric Oncology Nursing published online 9 June 2014

DOI: 10.1177/1043454214529369

The online version of this article can be found at:

<http://jpo.sagepub.com/content/early/2014/06/09/1043454214529369>

Published by:



<http://www.sagepublications.com>

On behalf of:



ASSOCIATION of PEDIATRIC
HEMATOLOGY/ONCOLOGY NURSES

[Association of Pediatric Hematology/Oncology Nurses \(APHON\)](#)

Additional services and information for *Journal of Pediatric Oncology Nursing* can be found at:

Email Alerts: <http://jpo.sagepub.com/cgi/alerts>

Subscriptions: <http://jpo.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

>> [OnlineFirst Version of Record](#) - Jun 9, 2014

[What is This?](#)

The Teen Impact Experience: A Webcast Pilot Project for Teens With Cancer and Blood Diseases

Journal of Pediatric Oncology Nursing
1–5
© 2014 by Association of Pediatric
Hematology/Oncology Nurses
Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1043454214529369
jpo.sagepub.com



Betty Gonzalez-Morkos, PsyD¹, Octavio Zavala, BS¹, Marcio Malogolowkin, MD²,
and Aura Kuperberg, PhD, LCSW¹

Abstract

This article discusses a novel service, webcasting of a live group, implemented in response to the 2009-2010 H1N1 Flu pandemic by Teen Impact, a program geared at providing social therapy to adolescents diagnosed with cancer or a blood disorder. To ensure that services were not disrupted to adolescents on treatment despite flu restrictions, Teen Impact obtained necessary equipment to webcast the group. A total of 6 Teen Impact members participated in the webcast portion of the group. Findings revealed that existing members who had participated in the face-to-face Teen group were left with feelings of dissatisfaction due to lack of physical interaction with other members. New members appeared to enjoy this option admitting that the webcast provided them with the ability to feel supported by others with similar stories without having to face unknown members in person. A positive outcome from this type of intervention resulted in the webcast serving as a stepping stone for future face-to-face participation.

Keywords

webcast, peer group support, oncology, technology, psycho-oncology

Background

For more than 5 decades, the Children's Center for Cancer and Blood Diseases at Children's Hospital Los Angeles has been a leader in the field of cancer and blood diseases. More than 1100 new patients and approximately 25 000 outpatients are seen annually (Children's Center for Cancer and Blood Diseases, 2013). Part of the Center's clinical program includes multiple services designed to address the psychosocial needs of the patient. Many of these services fall under the umbrella program known as HOPE (Hematology-Oncology Psychosocial & Education). HOPE offers psychosocial care and health education to children, teens, and their families during and after treatment for cancer and blood diseases. One of the programs under the HOPE umbrella, Teen Impact (TI), has provided professionally led year-round clinical social therapy programming since 1988. This includes twice a month groups for patients and their families, psychosocial activities such as 3-day retreats, adventure therapy overnights, and special events. The clinical goal of TI is to mitigate the psychological effects and social isolation that these diseases impose at specific developmental phases since a diagnosis of cancer or a blood disease and its treatments during adolescence creates unique challenges and disruptions of normal development (Eiser

& Kuperberg, 2007; Jones, 2008; Shama & Luchetta, 2007; Zebrack, 2011).

One of the crucial services that TI offers is the year-round, twice a month, social therapy groups provided separately for patients and for their family members. On average, 10 to 15 adolescents (13-19 years of age) attend the adolescent group; 8 out of 10 are off treatment. The therapeutic model for the adolescent group is that of a "facilitated support group," or a hybrid of group therapy and support group. Group facilitators, consisting of a psychologist, a social worker, and graduate students, facilitate the discussion, and group members determine the discussion themes. Unlike traditional group therapy, TI groups are year-round and open, thus attendance is not limited in size and participants can attend as much or little as they wish. As a result, attendance from one group to the next varies to some extent. However, a core group of

¹Children's Hospital Los Angeles, CA, USA

²Wisconsin Children's Hospital, Milwaukee, WI, USA

Corresponding Author:

Betty Gonzalez-Morkos, PsyD, Hematology-Oncology Psychosocial and Education Program, Children's Center for Cancer and Blood Diseases, Children's Hospital Los Angeles, 4650 Sunset Boulevard, MS# 54, Los Angeles, CA 90027, USA.
Email: bgonzalez-morkos@chla.usc.edu

“regular” participants attends most meetings seeking social support via participation in the group; current literature also emphasizes the importance of and need for social support among this population (Kent et al., 2013; Trask et al., 2003).

In the fall of 2009, the H1N1 flu pandemic resulted in an immediate change in hospital-wide policies across the country (Centers for Disease Control and Prevention [CDC], 2010). Visitor numbers were reduced for immune compromised patients, and patient involvement in activities that would jeopardize their health were also placed on hold (CDC, 2010). Within weeks of the onset of the pandemic and the release of the CDC recommendations, CHLA imposed strict infection control procedures that directly affected TI services. With short notice, TI was required to exclude any patient receiving chemotherapy or radiation from participating in any in-person group-based activity to reduce the risk of transmitting infection. Only adolescents that had completed all therapy for their malignancy were allowed to attend the groups. This abrupt interruption of services affected a subgroup of patients (on average 4 to 6 ongoing participants on active treatment) who were in particular need of support. Flu restrictions also changed routine TI recruitment efforts and activities since the program could no longer introduce and offer services to newly diagnosed patients or patients who had to resume treatment because of relapse. TI feared that those in greatest need were to be denied services given the outbreak of the H1N1 flu pandemic. In an effort to maintain continuity of care for regular participants who were now excluded and to continue to provide services to those adolescents on treatment with the greatest need, TI considered different ways to keep those excluded from the program connected to the rest of the group. Implementing a video webcast of the live TI face-to-face teen group would serve as a means by which members could remain connected and preserve the necessary social support of their peers. Thus, from October 2009 to March 2010, TI piloted a novel interactive video webcast of their live twice a month clinical social therapy groups.

Methods and Procedures

Participants and Recruitment

Adolescents on active treatment for cancer, who had attended at least 1 group meeting previously and now medically prohibited to attend, were informed of the off-site video webcast of the live group and invited to participate. However, due to the limited number of participants in the first webcast of the live group, TI extended the invitation to those living too far and to new patients who had never attended a TI group. In the end 3 groups were

approached: (a) long-time TI members on active treatment, (b) long-time TI members living too far away to attend, and (c) new members who had never attended the face-to-face group meetings.

Three days prior to the live group session, off-site members interested in participating in the video webcast were sent an email with the link to the website, a private password for upcoming session, and the conference call line number. A reminder phone call to interested patients was made the day before the group session.

A total of 13 adolescents were invited to participate via the Internet over the course of 3 meetings. Of those, 6 participated in the webcasts; 2 were female and 4 were male, ranging in age from 15 to 18 years old. Three of the 6 participants were long-term members of the program and 3 had never participated in the program previously. All adolescents approached signed HIPAA documents prior to participation. The adolescents agreed to provide feedback of their experience of the webcast sessions.

Setting

TI group meetings occur at CHLA in designated conference rooms. All groups are held in separate rooms concurrently. This separation maximizes peer-based support for each cohort. Distinct issues are discussed that pertain to that group and thus allows for normalization of concerns and issues.

Every group session begins with a confidentiality statement. The group members then introduce themselves by providing their name, age, diagnosis, and stage of treatment. Group topics are commonly identified by the group members, and in most cases, the facilitator is present to encourage elaboration or feedback from other members.

Some changes to the setting occurred as a result of the H1N1 flu pandemic. For instance, group sessions were no longer held in the conference rooms that had been utilized for years. Restrictions made it difficult to hold any type of group intervention within the hospital. As a result, the adolescent group was held in a hospital-affiliated auditorium across the street from the main campus. Additional changes included the presence of a camera and cameraman to transmit the webcast. A major change included the presence of remote participants. Remote participants used home computers to watch the live video feed of the in-person group over the Internet. They were required to use their home phones for audio capabilities.

Equipment

Equipment was selected to capture key elements of the live face-to-face group for those unable to physically attend the group sessions. Off-site members could see the

live face-to-face meeting but the live group could not see those logged-on through the Internet. Off-site members dialed a conference call line and communicated through a speakerphone or wrote messages through the website “instant messaging” window that was then projected onto a large overhead screen.

Implementation of the Webcast Intervention

Each group session began with an introduction by members in the face-to-face group circle followed by those utilizing the webcast option. To facilitate the group process, an added change included an alteration from a “normal group process” where participants randomly spoke and shared to a more formalized group process where participants were forced to indicate their desire to speak ahead of time. Group facilitators guided the discussion that included all participants and directed the speaking order. Off-site participants saw and heard the face-to-face group participants; however, the face-to-face group members only had access to hearing the off-site webcast participants. At the end of the group session, the facilitator dismissed the group, closed the phone line, and logged everyone off the website. The duration of each group session was 1 hour.

Survey and Evaluation

Once the H1N1 flu restrictions were lifted and the webcasting of the live group ended, an evaluation of the webcast, in the form of an interview, was conducted with TI members that took part in the intervention. The interview elicited thoughts regarding their experience, the effectiveness of the webcast and ideas for improvement. The interview included questions such as, “What did you think of the video webcast?” and “Should Teen Impact continue with this type of intervention?” Although a formal survey was not used, the responses obtained in the interview were considered in discussions for future program development.

Results

The video webcast portion of the TI program took place from October 2009 through March 2010. Over this 5-month period, a total of 9 meetings took place. Three of the 9 meetings included a live webcast. Of the 13 members invited to participate, a total of 6 members participated in the webcast sessions; 1 member participated twice whereas the other 5 members participated once. Three of the participants were ongoing TI members and had attended the face-to-face group on numerous occasions; the other 3 were new to TI and had never participated in the face-to-face group. Five of the 6 participants

were on treatment; only 1 participant was off treatment but participated because of distance (the member attends college out of state).

All participants were interviewed to provide feedback regarding their webcast experience. Differences were noted between long-term TI members and new members. Long-term TI members reported that the webcast sessions were not a good substitute for the live group meetings. New members stated in their feedback that they liked the webcast sessions because it offered them a sense of anonymity.

With the lifting of the flu restrictions at the end of March 2010, the webcast service was terminated and the TI groups resumed in their normal format and usual location. All members, regardless of treatment status were able to return and attend the live group meetings.

Discussion

It is well documented in the literature that peer support plays a major role in a cancer patient’s coping ability (Battles & Wiener, 2002; Evan & Zeltzer, 2006; Griffiths, Calex, & Banfield, 2009; Suzuki & Kato, 2003; Treadgold & Kuperberg, 2010; Ussher, Kirsten, Butow, & Sandoval, 2006; Woodgate, 2006). Numerous studies demonstrate the benefits of incorporating peer social support in medical treatment (Decker, 2007). Studies have acknowledged that peers with a cancer history offer different forms of support to an adolescent cancer patient that may be more beneficial than support received from family and friends (Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). The importance of peer support among cancer survivors increases as the individual progresses through the adolescent years (Derevensky, Tsanos, & Handman, 1998). Current literature also points to the rapid growth of the World Wide Web for support groups (Battles & Wiener, 2002; Hanley, 2009; Høybye et al., 2010; Suzuki & Kato, 2003; Till, 2004; Treadgold & Kuperberg, 2010; White & Dorman, 2001). The use of these types of groups versus the traditional face-to-face group has been touted as reducing stigmatization, increasing participation and increasing anonymity (White & Dorman, 2001). However, there is no evidence in the literature demonstrating the existence of live therapy groups providing simultaneous webcast of those groups to offsite participants.

In response to the infection control measures developed during the 2009 H1N1 flu pandemic, TI introduced a webcast of their live group therapy sessions. The webcast was created to provide continued peer support for on treatment patients that were unable to attend the live group therapy sessions. Thus, the evaluation of the TI experience using this combination will provide initial information on the usefulness of the service.

The present examination of the responses to the survey of the webcast suggested mixed feelings. For long-term TI members, the video webcast of the live groups did not fulfill the same psychosocial needs. Once the adolescent became a member of TI and accustomed to the face-to-face groups, this type of modality did not offer the same type of support. These long-term TI members did not feel fulfilled with the webcast and preferred the face-to-face contact. They missed the connections and interactions with other members. It appeared that having the initial experience of being an active member and part of a cohesive supportive peer group made it difficult to resort to obtaining support from this same group only via the Internet. This seems to underscore the value of live relational connections and peer interactions that cannot be replaced by a video webcast intervention.

The new members appeared to have benefitted from the webcast sessions. For these members, the video webcast group appeared to be an additional avenue of support. Those who had never participated in a face-to-face group stated that they felt connected and supported when hearing other members' stories. It also appeared to act as a stepping stone to the TI program. New members introduced to TI through the webcast sessions became more interested in TI other services offered. This suggests that initially this type of web-based modality may be easier and less intimidating than participating in the face-to-face meetings. It also offers new members anonymity, as they do not need to share more than a name and were not seen by the other group members. Although limited as a source of ongoing social support, the webcast approach may serve as a viable recruitment tool. Interestingly, though, only 1 member participated in the webcast group for a second group meeting, suggesting that perhaps the video webcast component had a limited capacity for social support for some of the new participants as well.

Limitations were identified with both the intervention and the examination of its efficacy. Major limitations of the intervention included limited time and resources to acquire a more sophisticated webcast solution. As a result, there were several interruptions to the group process caused by technical malfunctions of the equipment.

A primary limitation of the examination of the webcast's efficacy includes the lack of a formal survey before and after the intervention. Once the flu restrictions were lifted, informal questions were asked of those who had participated remotely in the webcast. Important information may have been obtained on the impact of participation prior to and after the intervention in a more formalized manner. Similarly, affective experiences of participants could have been identified and explored via formal measurement using validated instruments; a piece missing in this intervention.

In spite of these limitations, the experience with this intervention has practical implications. For some patients

unable to attend group meetings because they are immune suppressed, the option to attend group via a webcast may be the only option. By establishing a webcast intervention, adolescents with long hospital stays can freely participate in group therapy and find the social and emotional connections they may be searching for. Teenagers with cancer face tremendous challenges. Cancer and its often intensive and lengthy treatment can have a major impact on normal adolescent life. The wish for normalcy often results in profound isolation for teens who keep their cancer experience encapsulated and away from their healthy peers. Having an established and viable option for teens unable to leave their room or participate as a result of their medical treatments can reduce the adolescent's experience of isolation.

Current Research

Using the knowledge gained from this webcast experience, a formalized study is currently being conducted. TI secured a grant to fund a stable, long-term technical solution for providing group-based therapy to adolescents unable to attend groups in person. CHLA's Information Technology (IT) department helped identify the appropriate equipment and infrastructure combination that would best meet the needs of an isolated group of adolescents. TI chose to pilot the project with adolescents in CHLA's Bone Marrow Transplant (BMT) unit because infection control protocols at CHLA required these adolescents to have limited contact with others and prevented them from participating in group-based activities for long periods of time, thus making them vulnerable to extreme feelings of isolation (Fife et al., 2000; Molassiotis, Van Den Akker, Milligan, Goldman, & Boughton, 1995; Siegel, 2008). In October 2013, TI initiated its "Video-link" service, which by combining the use of tablet computers, video conferencing equipment, and the hospital's wireless system allowed teens in the BMT unit to attend long-established group meetings, albeit remotely, for the first time in the program's history.

Currently, there is no literature that describes a video-link service of this kind for hospitalized adolescents, much less patients on the bone marrow unit. Therefore, a study is presently being conducted to determine the feasibility and acceptability of this novel intervention.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

- Battles, H. B., & Wiener, L. S. (2002). Starbright world: Effects of an electronic network on the social environment of children with life-threatening illnesses. *Children's Health Care, 31*(1), 47-68.
- Centers for Disease Control and Prevention. (2010). *2009 H1N1 flu*. Retrieved from <http://www.cdc.gov/h1n1flu>
- Children's Center for Cancer and Blood Diseases. (2013). Retrieved from http://www.chla.org/site/c.ipINKTOAJsG/b.3763823/k.6593/Center_for_Pediatric_Cancer_Blood_Diseases__Hematology__Oncology.htm#.UuGsbPulaUk
- Decker, C. (2007). Social support and adolescent cancer survivors: A review of the literature. *Psycho-oncology, 16*, 1-11.
- Derevensky, J. L., Tsanos, A. P., & Handman, M. (1998). Children with cancer: An examination of their coping and adaptive behavior. *Journal of Psychosocial Oncology, 16*(1), 37-61.
- Eiser, C., & Kuperberg, A. (2007). Psychological support for adolescents and young adults. In A. Bleyer & R. D. Barr (Eds.), *Cancer in adolescents and young adults* (pp. 375-786). Berlin, Germany: Springer-Verlag.
- Evan, E. E., & Zeltzer, L. K. (2006). Psychosocial dimensions of cancer in adolescents and young adults. *Cancer, 107*, 1663-1671.
- Fife, B. L., Huster, G. A., Cornetta, K. G., Kennedy, V. N., Akard, L. P., & Broun, E. R. (2000). Longitudinal study of adaptation to the stress of bone marrow transplantation. *Journal of Clinical Oncology, 18*, 1539-1549.
- Griffiths, K. M., Calcar, A. L., & Banfield, M. (2009). Systematic review on Internet support groups (ISGs) and depression (1): Do ISGs reduce depressive symptoms? *Journal of Medical Internet Research, 11*(3), e40. doi:10.2196/jmir.1270
- Hanley, T. (2009). The working alliance in online therapy with young people: Preliminary findings. *British Journal of Guidance and Counselling, 37*, 257-269. doi:10.1080/03069880902956991
- Høybye, M. T., Dalton, S. O., Deltour, I., Bidstrup, P. E., Frederiksen, K., & Johansen, C. (2010). Effect of internet peer-support groups on psychosocial adjustment to cancer: A randomized study. *British Journal of Cancer, 102*, 1348-1354.
- Jones, B. L. (2008). Promoting healthy development among survivors of adolescent cancer. *Family Community Health, 31*, S61-S70.
- Kent, E. E., Smith, A. W., Keegan, T. H. M., Lynch, C. F., Wu, X., Hamilton, N. S., . . . Harlan, L. C. (2013). Talking about cancer and meeting peer survivors: Social information needs of adolescents and young adults with cancer. *Journal of Adolescent and Young Adult Oncology, 2*, 44-52.
- Molassiotis, A., Van Den Akker, O. B. A., Milligan, D. W., Goldman, J. M., & Boughton, B. J. (1995). Psychological adaptation and symptom distress in bone marrow transplant recipients. *Psycho-Oncology, 5*, 9-22.
- Shama, W., & Luchetta, S. (2007). Psychosocial issues of the adolescent cancer patient and the development of the teenage outreach program (TOP). *Journal of Psychosocial Oncology, 25*, 99-112.
- Siegel, S. (2008). Psychosocial considerations in hematopoietic stem cell transplantation: Implications for patient quality of life and post-transplant survival. *Community Oncology, 5*, 407-411.
- Suzuki, L. K., & Kato, P. M. (2003). Psychosocial support for patients in pediatric oncology: The influences of parents, schools, peers, and technology. *Journal of Pediatric Oncology Nursing, 20*, 159-174.
- Till, J. E. (2004). Cancer related electronic support groups as navigation-aids: Overcoming geographic barriers. *Journal of Cancer Integrative Medicine, 2*(1), 21-24.
- Trask, P. C., Paterson, A. G., Trask, C. L., Bares, C. B., Birt, J., & Maan, C. (2003). Parent and adolescent adjustment to pediatric cancer: Associations with coping, social support and family function. *Journal of Pediatric Oncology Nursing, 20*, 36-47.
- Treadgold, C. L., & Kuperberg, A. (2010). Been there, done that, wrote the blog: The choices and challenges of supporting adolescents and young adults with cancer. *Journal of Clinical Oncology, 28*, 1-9.
- Ussher, J., Kirsten, L., Butow, P., & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine, 62*, 2565-2576.
- White, M., & Dorman, S. M. (2001). Receiving social support online: Implications for health education. *Health Education Research, 16*, 693-707.
- Woodgate, R. L. (2006). The importance of being there: Perspectives of social support by adolescents with cancer. *Journal of Pediatric Oncology Nursing, 23*, 122-134.
- Zebrack, B. (2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer, 117*(10 Suppl.), 2289-2294.
- Zebrack, B., Bleyer, A., Albritton, K., Medearis, S., & Tang, J. (2006). Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer, 107*, 2915-2923.

Author Biographies

Betty Gonzalez-Morkos, PsyD, is a licensed Clinical Psychologist and Clinical Coordinator of the Teen Impact Program in the Division of Hematology, Oncology and Blood and Marrow Transplantation at Children's Hospital Los Angeles.

Octavio Zavala, BS, is Program Administrator of the Teen Impact Program in the Division of Hematology, Oncology and Blood and Marrow Transplantation at Children's Hospital Los Angeles.

Aura Kuperberg, MD, is Founder and Director of the Teen Impact Program in the Division of Hematology, Oncology and Blood and Marrow Transplantation at Children's Hospital Los Angeles.

Marcio Malogolowkin, PhD, LCSW, is the Medical director of the MACC Fund Center at Children's Hospital of Wisconsin and Chief and Professor of Pediatric Oncology and Bone Marrow Transplantation at the Medical College of Wisconsin.