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Implementation of an Online Adolescent Oncology Support Group

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Implementation of an Online Adolescent Oncology Support Group

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Abstract

Adolescence is a time for social and emotional growth and learning how they interact and engage in the world around them. When an adolescent is diagnosed with a life threatening cancer diagnosis, it can have a substantial impact on their ability to maintain social and emotional connections with their peers. Disruptions in school and peer relationships can lead to isolation, withdrawal and poor coping. Many factors contribute to a teens inability to stay connected with their current peer group, as well as make it difficult to develop and meet new peers in the hospital setting that are also coping with a cancer diagnosis. With an increase in adolescents use of technology, phone use and social media, an online support group was established for teens undergoing and 1 year post cancer treatment in a rural hospital setting. The group was implemented, facilitated and evaluated by a certified child life specialist. This paper will examine the effectiveness of an online platform for teens diagnosed and undergoing cancer treatment for improving peer relations, increased coping, and expression of feelings.

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Introduction

The adolescent population of patients with a cancer diagnosis has many aspects of development to consider in how they cope with the effects that illness has on them, both physically and emotionally. As a child life specialist working with this population of patients, there is often multiple requests from caregivers and parents as to what type of resources are available for their child. Many of those inquiries are about adolescent support groups. Oftentimes, teens share that it is the separation from their friends that causes them stress in their everyday life. Adolescent patients with a cancer diagnosis have shared with the child life specialist at this institution, that staying connected to peers that understand them and can relate to what they are going through would be helpful to them. Child Life Specialists play an important role in providing adolescents with appropriate coping techniques and outlets for expression of feelings. As a child life specialist, our mission is “to reduce the negative impact of stressful and traumatic life events and situations that affect the development, health and well-being of infants, children, youth and families.” With that, a core value in our profession is being “committed to relationships built on trust, respect and professional competence which contribute to the development of confidence, resilience, and problem-solving skills that enable individuals and families to deal effectively with challenges to development, health and well-being.” (Child Life Council, 2011). Through play, preparation and expressive arts child life specialists are able to meet this need for most children, youth and families in the hospital setting. However, a typical struggle for most child life specialists working with teens with chronic illness is providing opportunities for teen peer relationships. The nature of the disease, setting, and developmental age band often leads to isolation due to treatment or distance of the hospital to the family home.

Therefore, the implementation and utilization of an online support group will allow for a child life specialist to provide the space for teens to build relationships, confidence, problem solving skills and resilience, core foundations of the CCLS mission and value.

The pediatric oncology child life specialists role as the moderator for the group will be beneficial for adolescents involved. Hicks and Davitt, 2009, stated “child life specialists can be effective facilitators of support groups given their knowledge of growth and development and their relationships with the children and adolescents.” The established therapeutic and supportive relationship that the child life specialist already has with the teens involved makes for a consistent and easy transition for the facilitation and involvement in the group.

Literature Review

Online support systems for teens have been shown to have positive impact on belonging, self-esteem and identity. (Davis, 2013). In addition, they have also been shown to add a sense of empowerment that the impact of writing and expressing themselves online can do. (Barak, Boniel-Nissim, Suler, 2008).

Matthew Hunt, a counselor from Counseling on Demand, stated ‘One of the biggest advantages teenagers can get from any type of support group is the realization that they are not alone as they may think’, when discussing the benefits of online support groups. A study done at Children’s Hospital at Philadelphia in 2016, interviewed adolescents and young adults with a cancer diagnosis, where 75% of them endorsed the need for a support group. Of these adolescents and young adults surveyed, 56.5% stated the best way to connect to other patients like them was one on one or in person. Providing an outlet for adolescents to be able to connect with other peers experiencing a similar diagnosis and treatments can provide additional support.

Feeling supported, having a connection to peers and a sense of belonging can provide benefits in coping with their cancer diagnosis. This will help aid in the adolescent missing out from their non cancer peer group they are familiar with and missing in their home environment due to their illness. A support group for teens coping with similar situations allows the peer relationships to continue and help in their sense of belonging and identity development. Being involved in a support group where everyone has the same diagnosis will positively impact their sense of identity and a sense of belonging with others who understand what they are going through both emotionally and physically. Teens often belong to groups with similar interests in non health related instances with friendships, cliques and crowds as they are drawn to individuals with similar experiences to serve their emotional and security reasons. (Lightfoot, C. 2103).

Research continued to state that message boards such as Facebook was second at 50.9% in providing the next best opportunity for teens to be connected. (Barakat, L, Galeteri, L., Szalda, D & Schwartz, L., 2016).

Digital media, technology and social media offers a new and current outlet for teens to communicate and connect with peers. The use of technology for adolescents can have an impact on their identity. (Davis, K. 2013). When provided with a positive online social model, adolescents can continue to feel supported, provide support, and have a positive impact on their identity. An article written by Fukkink and Hermanns in 2009, shared in their research that 80% of girls vs. 20% of boys participated in a support group study to look at support groups use with phone calls and online components. Research shared from a 2001 survey from Pew Internet and American Life Project showed that 48% of online teens believed the internet has improved relationships with friends and that 61% of those teens surveyed did not feel that the use of online

and internet communication took away from time with friends. In addition, a majority of 80% shared they use the internet to maintain friendships. (Subrahmanyam & Greenfield, 2008).

Developmental Aspects of an Adolescent with cancer

Adolescence is a time for social and emotional growth, as well as developing a sense of identity. When an adolescent is diagnosed with a cancer diagnosis, it can have a dramatic effect on their identity, peer interactions and emotional well being. (Elwell, Grogan, Coulson, 2010). For an adolescent, the majority of their time is typically spent with a peer group and one of their primary developmental focus is on social relationships. (Lightfoot, C., 2013). Time with friends contributes to a teens sense of autonomy and independence with the shift of priority being with peers rather than their parents. When an adolescent is diagnosed with cancer, they are now forced to rely on their parent and spend more time with them than they typically would during normal adolescent growth. The adolescent's sense of identity can be challenged when areas of autonomy is taken away from them due to the decrease in peer interactions and lack of choices they are able to make. Lightfoot, 2013, discusses how an adolescents autonomy can add to an increase in parent and adolescent conflict because of the differences the adolescent and parent may feel regarding personal space, boundaries and beliefs. Cognitive changes in the brain of an adolescent can affect their emotional behaviours and the decision making process that happens at this time. As adolescents are experiencing a time of development where they engage in risk taking behaviors, research by Mariecel and Delaet, 2015, state that young adults and adolescents with chronic medical conditions are as likely and perhaps more likely to engage in health risk behaviors due to the experiences they have encountered. Additional research by Nylander,

Seidel & Tindberg, 2013, state that adolescents with chronic illness who engage in risk taking behaviors need to have more support from the professionals that work with this population.

Adolescents diagnosed with cancer have been found to experience many stressful events and changes, both emotional and physical as a result of their illness and treatments. The numerous side effects from treatments, such as chemotherapy can cause hair loss and weight gain, can add to the factors that have an effect on their emotional health in regards to self esteem and identity. Looking different than your peers or how you would like to look can cause a decrease in self esteem. With cancer occurring more frequently in adolescents and young adults than in younger children, (National Cancer Institute, 2018) having support systems in place for this population during this stressful time is necessary. Approximately 102,130 adolescents and young adults ages 15-39 were diagnosed with cancer in 2010-2014. (NCI). A teen must undergo treatments in the hospital which forces them to miss out on school and social events ranging from a prom, to sporting events to missing a movie night with their friends. For a teen, undergoing treatment for a cancer diagnosis, requires them to be away from home and school and much of their time is spent at the hospital or with their caregivers at home, away from peers. This can make them feel excluded and isolated from what is their normal peer support system.

Feeling supported, having a connection to peers and a sense of belonging can provide benefits in coping and normalcy with their cancer diagnosis. Having a network of support will help aid in the adolescent missing out from their non cancer peer group they are familiar with and missing in their home environment due to their illness. A support group for teens coping with similar diagnosis and situations allows the peer relationships to continue to build and will help in their sense of belonging and identity development. The consideration and involvement in

a support group where everyone has the same diagnosis will positively impact their sense of identity and a sense of belonging with others who understand what they are going through both emotionally and physically. A support group can allow for the outlet needed for the adolescent to be able to make independent choices and control without the presence of their parent.

Background Information of Hospital Site

This hospital site which hosted the online support group is a large medical setting located in a small New England state in a rural setting. It is an academic medical setting and the only Level I trauma center. The children's hospital is located within the larger medical setting and is the only children's hospital and pediatric oncology program in the state. The pediatric oncology patients are seen in the Cancer Center clinic, three days a week and are admitted to the inpatient pediatric and adolescent unit or the pediatric intensive care unit for their inpatient admissions.

In 2017, there were 30 new diagnosis of all pediatric oncology patients ranging age from 0-19 years of age. Of those patients, 10 of them were adolescents, 6 girls and 4 boys.

Historically, the child life specialist has done a teen support group where the patients met in person while they were in clinic or inpatient at the same time. Over the 13 years, as the child life specialist, who has facilitated these groups, there have been fluctuations in participation ranging from no interest at all, to 2-3 girls meeting and becoming friends in person, to having a group with meetings in clinic with 4 to 6 teens. These varying relationships are consistent with how many adolescents are on treatment at the same time as well as when there are more girls in the older adolescent population that would like to engage with the other patients. As the age at which one is diagnosed is unpredictable, there has been times when there are only a few teens going through active treatment at the same time.

With this hospital being located in a rural and small state, the travel time for many patients can be up to 2 hours one way. Institutions where teens with cancer are diagnosed and receive their treatment, the geographical location of the medical center poses challenges for teens to develop and build upon relationships with other teens also experiencing a cancer diagnosis. This is often due to the distance and time it takes to travel back and forth, financial and work related obligations of the caregiver as well as the needs of other children in the home. Therefore, challenging for caregivers to return to the hospital with teens for an in person support group with other adolescent patients.

Many patients and families have preferences for when to schedule hospital admissions as well, to help with missing less work or school, which can interfere with trying to schedule the teens patients to come on the same day. As a result of a variety of factors, the ability to provide a meaningful experience through an on site, in person adolescent support group was limited. The literature and research available on the benefits of teen support groups coupled with the location of the hospital and appointment timing being a potential barrier to participation, as well as, understanding that teens rely on electronic devices for much of their social interaction, it was decided to pursue trying an online support group as a means to promote and maintain connections with other teens.

Assessing Interest Level of Teen Patients:

Conversations were had with each of the 8 adolescent patients that are on active treatment for a cancer diagnosis. Verbally there was 100% positive interest in participation of this group.

All of the caregivers of the adolescent patients were in agreement and supportive of their child participating. Many of the parents this writer interacted with often asked if this institution had a teen support group as they felt it would be helpful for their child.

For a teen that is newly diagnosed with cancer, they will be informed of the support group resource after their cancer diagnosis when the CCLS has met with them in the first or second interaction, if the timing is appropriate. They will then be assessed to be enrolled in the group when they are receptive and feeling ready to participate. If the teen had not signed up after the first conversation was had, this writer and facilitator would share this resource again at their next clinic visit to again assess for interest. For the teens who were already on treatment and had met criteria for group participation the offer to participate was made at the start of the group in January of 2018.

Creation of Group, Guidelines and Consent Process

Due to the unpredictability of when an adolescent is diagnosed with cancer, the group will be an open ended group, where members can join as they are diagnosed and feel ready to participate. (American Psychological Association). This will be helpful having this group be an open group, as members can be removed from the group if they no longer meet the criteria for participation, such as, they are over 18 years of age or have been off therapy for more than one year. Research in looking at the success for open access group has stated that promoting open access groups may increase feelings of empowerment. (Gillard, White, Miller, Turner, 2015).

The consent and rules of participation was created by the CCLS, as well as staff from this hospital's office of general counsel and the law offices of [REDACTED].

This consent was under review from the hospital and the law offices to ensure that patient's privacy was taken into consideration as well as the privacy of the institution. (Appendix A) Several phone meetings were had with the law office and office of general counsel whose role was to specialize in the creation of consents that address privacy of patient and online social media use. From these meetings with the lawyers the support group consent and rules of participation was created in order to clearly define what was appropriate behaviour and purpose of the online group. Since the age band for the group is 13-18 years, these guidelines help to protect the online social media use of a minor. The consent and rules were reviewed with each teen member and their caregiver to allow for participation.

A few of the of the rules expressed the need for the appropriate use of language and behaviour. This guideline addresses the need to keep comments open, honest and respectful so all can feel able to participate and safe when doing so. One should not feel judged or made to feel bad for posting comments that could already feel vulnerable to be making. It speaks to the importance of offering support to someone instead of telling another individual what they should do or giving advice on how to make themselves feel better. Feeling empowered and being able to share openly in a group is a key factor in the success of a group, as stated in the literature by Ariel Botta in the concept of strengths-based group work with children. (Botta, 2009). These patients may be experiencing additional stressors in their lives in addition to their medical illness. Having this outlet of support allows for them to strengthen their support system and build upon their skills to enhance coping. Botta, in addition stated that there are two indicators of that contribute to children's resilience in the face of adversity. One being, "the perception by some of adversity as a challenge and opportunity to grow and learn tends to result in better

coping with stress than those who view it as a roadblock.” The second is “having a strong social support.” In integral component for the success of the group was that it a safe place for teens to express themselves.

Another important factor included in the rules of participation addresses the support group is not the appropriate place to receive or recommend any medical advice. If patients were to discuss or share medical information or inaccurate information, the child life specialist would address it on the page by suggesting a medical provider participate in answering questions, as well as address it in person at the next clinic visit. When a patient is no longer eligible to participate in the group due to age restrictions or off treatment over a year or the teen has decided to no longer participate the consent states that the departing teen must “say goodbye” to the teens in the support group. Once the finalized consent was created and permission was granted to use, the CCLS met with the participant and their caregiver to review and have the consent signed.

Creation and Structure of Google plus Community Page

It was determined that the group would be in the form of a Google plus Community Page. Google plus community was chosen due to the privacy settings the moderator could set up prior to “inviting” teens to participate. Accessibility was another factor in determining the platform. It was decided to use a platform that can be easily retrieved from any device. The Google plus community support page can be accessed on a handheld device, such as a smartphone or tablet, as well as a computer. In order for the moderator to “invite” teens to participate in the group each teen needs their own email address. All teens shared that they have email addresses already from school or personal use. Current trends, point to increased amount of time one uses their

phone. Research done by Kohut, et al. stated that adolescents who did express interest in online support groups stated the resource should be “private, web and app accessible and easy to navigate...”, which the use of Google plus community has accessibility both on a computer as well as an app on the phone or handheld tablet. With the increase in cell phone use and dependence in adolescents as being an important component in a teens everyday life as shared in research by Chh-hung Leung in 2016, the ability to access this on their phones will allow for easier access and potentially increase how often teens communicate with the group.

The Google plus Community page establishes it as a private page in which only members can see or have access to the page, the moderator has the ability to screen each post before it is added to the page as well as the ability to remove a member from the group if the need arises. This could be needed in the case of an inappropriate posts on the page or the death of a group member.

The Google plus page has multiple sections within the page. (Appendix B). There is a Discussion section, which the child life moderator or members can post weekly or as often as needed to prompt conversation amongst the teens. The topics can range from sharing something about themselves, to coping with the return to school, or friendships. A resource page will contain information that will have information regarding supportive teen websites, camp information and events at the hospital that they may be interested in participating in. A website section will list supportive sites that have been reviewed by the moderator prior to sharing. In addition, there will be a college scholarship section for those adolescents interested in applying to college and may be eligible for certain scholarships due to their cancer diagnosis. Lastly, there is a separate section on the page that lists what the group's guidelines are. This is to ensure

individuals are reminded of what the guidelines are and have access to review at any time. This is also to help protect the child life specialist in the event that an adolescent uses the group inappropriately and needs to be removed from the group.

Implementation and Roll Out

Each adolescent patient and their parent reviewed the Rules of Participation and signed the consent to allow for participation in the group.

Based on the criteria of up to the age of 18 years of age and up to one year off therapy the group selection was created. The first email invitations were sent to 8 participants, 3 boys and 5 girls. There were two adolescents that did not get asked to participate in the group at this time due to their history of and current use of alcohol and disclosed use of recreational marijuana. Each of girls accepted the invitation and joined the group, the 3 boys never accepted the invitation to join. This left the group with a total of 5 adolescent girls online. Of the 5 girls, there was one 18 year old girl who just completed treatment for ALL, one 16 year old girl who has almost completed therapy for Ewing sarcoma, one 15 year old girl with Acute Myeloid Leukemia (AML) almost at the end of her treatment, a 14 year old girl who is 2 years into her treatment for Acute Lymphoblastic Leukemia (ALL) and one 13 year old girl who has Hodgkin Lymphoma. None of the participants had met prior to the enrollment into the group.

A trial period of 8 weeks was given to the group, starting on January 1st of 2018 and concluding on March 1st, 2018. This amount of time was felt to be adequate to determine if changes needed to occur and to allow time for the adolescents to participate as needed.

Group Participation

Prompts and Discussion

Each week the CCLS would post a new Discussion prompt. Only once did a teen start their own discussion prompt. All others were done by the CCLS and the girls would comment below the original post. The first week post was to welcome everyone to the group. They were asked to introduce themselves and to feel free to share something about themselves or share if you have a New Years Resolution. One teen shared her “Hello!” and her name on that first week. The discussion question asking if anyone had a good or group name for the group received a couple replies, being “Teens to Teens” and “Just Keep Smiling”. The group ended up choosing “Teens Connecting” as the name of the group.

Another discussion post was “Who is someone you feel you can always talk to?” There was one reply to this, when the teen stated “Her mother and best friend”.

Into the second month, one teen posted her own post stating “Hey everyone! I hope you are having a happy and healthy start to the year. I would love to connect and talk with you all. Please feel free to reach out anytime, about anything.” One teen replied, “Hi, Thank you!”

Another discussions prompt was “What is the hardest part of being a teen while going through treatment for cancer?” One reply was, “the hardest part for me was my relationship with my friends. During the beginning of my treatment I had a ton of support form my friends and classmates. I found that as time went on I was sort of forgotten.”

When prompted by the Discussion question, “What are some things that help you cope when you are having a stressful moment?” One teen shared “...my favorite thing to do to de-stress is to pull out a book or listen to music and focus on the moment I’m in.”

One patient commented on the page “I wake up every morning and set one goal for myself everyday. Whether it’s as simple as reading a chapter in a book, or cooking dinner for my family. I find that it’s nice to control this aspect of my life after not being able to control for a few years.”

These posts are an example of the ability for this adolescent to gain control over her circumstances and maintain some independence since she needs to rely on her mother for her care during her illness. This particular patient, who is an only child, had shared prior to the start of the teen group in a discussion during one of her clinic appointments with this CCLS, that she had minimal friends prior to her diagnosis. This venue gave her a social outlet that she had control over. She needed to rely on her mother to bring her to her appointments and spent the majority of her time at home with her parents. By participating and taking control of what she decided to post to the group, she was able to create her own sense of identity and strength. As the oldest participant she seemed to take on a role of mentoring other patients by modeling for them how she copes in hopes that they might follow her example or share one of their own.

Some responded with a “plus 1” indicating they had read it indicating they liked her post. Online support groups have been shown in the research by Barak, Boniel-Nissim and Suler, to contribute to a sense of personal empowerment for people in distress that the impact of writing and expression of emotions can have. (Barak, Boniel-Nissim & Suler, 2008).

The CCLS posted at one point, the question, “If some of you are in clinic at the same time as each other would you like me to introduce you?” The answer from 3 out of 5 participants was yes.

Throughout the week, inspirational quotes and additional comments to the discussions were added. These quotes were based on the facilitators knowledge and previous relationship with the teens involved in the group and were motivational in nature. These consisted of simply, “You got this!” to, “Whenever we begin to feel as if we can no longer go on Hope, whisper in our ear to remind us that we are strong”, by Robert Hensel. At the beginning of March, around Dr. Seuss’s birthday “Why fit in when you were born to stand out!” by Dr. Seuss was posted. This post was shared as a way to try and engage all members and recognizing that there are areas of themselves that are not the same as everyone else around them. Often many of the posts were more positive in nature and may have been not allowing the recognition of it being ok to not always be happy and having to always have a good day. A look at a way to discuss and share the full range of emotions will be considered when continuing this group.

There was also a poll conducted for preference on how to use the page as well. It was to see if the group would like to try a “live” synchronous session. The feedback from that poll was 100% in support of participating in a live meeting.

The two main and consistent contributors to the group were the 18 year old girl and the 16 year old girl. This could be speculated due to their personalities or temperament, but may also be due to their older age than the other participants. The participants shared interests they had, such as reading and relaxing with friends when they were able. Support was provided by one teen on a consistent basis where she shared what helped her when she was admitted to the

hospital as well as when she was missing her friends and school. Although, the other girls did not comment much, they often “plus 1” the post, as you are able to do in Google plus community, so you are aware it has been read, agreed with, or liked the comment. It is difficult to fully assess the effects this had on coping with treatment, but it could be that these comments allowed the others reading them to not feel as they were in isolation with their illness. These experiential posts and comments allowed for the participants to connect in a way to their peers that they had been unable to do since the diagnosis of their cancer. They found a connection with other teens that are similar to them, with the benefit of decreasing the feeling of isolation as they cope with their illness.

By allowing the adolescents to post in a manner that is allowing them to share their thoughts and feelings is providing them with a strengths based perspective and approach to coping. By enhancing their support systems and social support, it is helping to build resilience and coping. (Botta, 2009).

Addendum

The open enrollment of the group was beneficial, as it is unpredictable when an adolescent was diagnosed with cancer. Having the open group allowed new members to be invited after the initial start date as well as when they felt ready to participate. Since the end of the pilot on March 1st, 2018, two more teens have been added to participate in the group.

A consideration of reaching out to adolescents who have been off therapy for longer than one year may be beneficial in not only increasing the numbers of adolescents but also have adolescents that may be able to offer more support in what it is like to be all done with treatment. The creation of an additional community group page for adolescents that have been off treatment

for longer than one or two years would also be a consideration. I feel that the most active participant was the 18 year old patient who had just completed therapy. An additional possible goal would be having patients like her, be used as mentors for the group, to help engage conversations and activity with newer members.

During the group, one member died unexpectedly. The decision was made by this writer and facilitator to not post the information of the death on the group page. This was due to the fact that they had not all met in person, along with the fact that the group had only been underway for four weeks played a role in the decision. The fact that they are all under 18 years of age, except for one patient, parental permission and their awareness was needed before I shared this information. In addition, it would have been a HIPPA (Health Insurance Portability and Accountability Act) violation. Some members of the group had not posted yet on the group, so it was hard to determine what their involvement status was. Another rationale for not posting it on the community was due to the potential need for the in person support that this groups is not able to provide as well as, the unpredictability of when a member may read the post, with the possibility of no one being present to provide support to the adolescent when they read the news. In the future, if there are other members of the group that die, each case will be considered based on the wishes of the family, the group members and HIPPA to determine what the best decision in order to provide support to the members of the group at the time. Prior to the start of this online group, when a patient has died, the CCLS has known what teens have met in person and the protocol that has been used, is to first reach out to the parents by phone call or in person at the next clinic visit, if it is within that same week to let them know that another teen that their child knows has died. The parent can then determined what are the best decisions for them. This

protocol will be best used with the online group as well as the CCLS of the group who will be monitoring the communication between patients that happens online.

In this case, the decision was made to share the news with the parents of the children who had been posting on the group page. I shared this news when I saw them at their next clinic appointment. The parent then made the decision to share the news with their child with the support of the child life specialist present.

An informal discussion was had with 2 of the participants that did not contribute any posts or comments to the group. When asked, if there was something different they would have liked to see on the page, both had similar responses in that they liked just looking and seeing what others had posted. They liked the motivational pictures and quotes. One stated, “just knowing there were other teens here like me was helpful.”

Reflection on Clinical Practice

Due to my participation and moderating of this group, I have found that the relationships I have with the teens have developed in a different manner. There is an increased sense of trust and what would feel like an unspoken bond. It feels as though we have a deeper connection, as they may post on the community page comments that they don't want to say in front of their caregivers that are in the room with them when I visit them in the cancer center. There is more eye contact and smiles when I enter the room than prior to the start of the group. It is still very much a therapeutic relationship with mutual trust and respect, but feels as though there is more depth to the patient and child life specialist relationship. The posts the teens made are in regards to their friends, support and general coping. The teens need that outlet away from their parents to discuss this need, one teen shared “the hardest part for me was my relationship with my

friends. During the beginning of my treatment I had a ton of support from my friends and classmates. I found that as time went on I was sort of forgotten.” This speaks to the desire for teens to feel connected to a peer group and aligns with much of the research on the support online groups can be, to “offer relief and improved feelings.” (Barak, Boniel-Nissim & Suler, 2008, p. 1868) as well as a place to “express and explore their identities.” (Davis, 2013, p.2282). This group has continued to be utilized with an additional plan to create a synchronous group, as well as the encouragement for the patients to meet in person when treatment and hospitalizations allow for it. The group is continuing to add new adolescents as appropriate and when they meet the criteria for participation. The goal for an increased sense of connection to peers with a cancer diagnosis and the hope to decrease possible feelings of isolation will continue to be the focus of this group. This group will be adapted as needed based on the feedback the participants provide to the child life specialists, along with any identified needs seen by the child life specialist throughout the use of the group.

Conclusion

The initial start and pilot of this online teen oncology group has positive pieces to build upon for further involvement and participation. I learned that despite getting verbal interest from some of the adolescents, in this case, the male patients, may not have necessarily been interested. There was one male patient, in which the parents appeared more interested in joining than the patient did, stating “he would really like to do that.” When this patient was reminded of his invitation, he stated to his parents, “Yeah, I think I’m good.” This patient was assured, it was completely optional and he did not need to participate if he did not want to. In considering getting more male patients involved in the social support component, the continuing of trying to

connect them in person in the clinic setting to meet other teens if they are receptive should still be considered and offered

As more adolescents are diagnosed with cancer the numbers of the group will increase with hopes that the participation component may increase as well. In this instance, the open rolling group format makes sense, as new members can read what present and former members have posted to get a feel for the group. It was helpful to have an older adolescent who had just finished treatment and was treated for 2 years, be a role model and mentor for the group. For the group members that participate, they shared that it has been beneficial in knowing there are other teens similar to them. The two patients that communicated primarily on the group page have quite different personalities in my opinion. I found that the common connection of their cancer was the primary bond that allowed them to feel connected. The patients did not ever make plans on the group page to try and meet in person. Two of the patients have since met in person, which has appeared to be a supportive connection. It has allowed them to feel less isolated as well as having a peer that understands their challenges and illness. They also shared that it has been a safe place to share feelings regarding the effects of diagnosis on friendships and have felt as they were encouraging others as well. Some research has stated that "...the vast majority of adolescents report being "lurkers" who enjoy reading about others' experiences but refrain from actively participating online." (Kohut, 2017, p. 214). I would have thought that more participation from each member would have happened than actually occurred, as I was anticipating it to be much more of an active community page. With some teens who prefer to read posts and not share, the posting of additional supportive and empowering blogs, such as The Mighty (themighty.com) may be beneficial for those patients.

For the younger adolescents who were 13 and 14 years old, it is a text heavy format, this may have had an influence on their participation level as they could have felt intimidated by the older adolescents participation. Therefore encouraging them to share using other formats of pictures or videos might be a way to increase engagement.

Due to the rural setting of this hospital, this group was able to maintain success for the small amount of patients that engaged as they may not have been able to do so otherwise based on their distance from the hospital. The adolescents that participated were able to gain control and increase a sense of independence from their parents during their time in using the support group. This allowed for them to create a new peer group that was able to formed a sense of belonging again.

Anticipation of the continued growth of the adolescent online support group and the changes that will be made, will make for a rich supportive resource that will benefit the adolescent oncology population at this site.

Appendix A
Consent Form

Online Support Group Participation Consent Form

I, _____, parent of minor child
_____, hereby consent for my child to participate
in _____
(_____) Online Support Group for teens undergoing cancer treatment at _____
Online Support Group” or “Online Support Group”).

Description of Services: _____ offers a professionally-facilitated Online Support Group for adolescents between the ages of 13 and 18 who are undergoing cancer treatment at _____
Children must be at least 13 years old to participate. In order to encourage teens to participate actively, parents and outside observers will not be allowed to participate in the Online Support Group. Participation in the group is completely voluntary. The Online Support Group does not provide counseling or medical advice, but is an educational and support program for teens who are dealing with the effects of cancer treatment, and provides a forum in which they can gain support from others who are experiencing similar situations. Please note, this support group will not provide group counseling, even if the group facilitator may be a professional counselor. The Online Support Group is not intended to be used for medical consultation, nor should it be considered medical advice. All specific or urgent questions should be directed to your child’s health care provider.

Support Group Platform: It is important to note that the platform used for the [REDACTED] Online Support Group is a Google Community platform, not a [REDACTED]-designed platform. While the Online Support Group platform will be private and by invite only, and will be managed by a CHaD facilitator, your child's use of the Online Support Group will be subject to Google's privacy policy and terms of use. You should review the Google Community privacy policy and terms of use carefully, as they include information related to Google's information collection practices through the platform (including information about your child), and how Google uses such information. If you do not agree with Google's privacy policy or terms of use, you should not sign your child up for the Online Support Group.

Rules of Participation: [REDACTED] can remove participants from the Online Support Group at any time in its sole discretion. Your child must abide by the following rules for participation in the [REDACTED] Online Support Group. You should review these rules with your child:

- 1) Participants must introduce themselves when first entering the Online Support Group (first name is sufficient). Otherwise, participants must not share any personal information in the Online Support Group, such as phone number or address.

- 2) Open and honest communication is encouraged; however, participants must be mindful of how words may impact others. Conversations should at all times be kept safe and non-triggering.

- 3) Be patient and kind with other users and respect other individuals' opinions, statements, ideas, and shared stories or experiences, even when quite different from your own.
- 4) Be respectful of conversational space and try not to dominate the conversation.
- 5) Offer support, not advice. Offer "what worked for me" and let others decide for themselves if it might work for them too.
- 6) Do not use the Online Support Group if you are affected by drugs or alcohol.
- 7) Do not post any statement which you know is false, inaccurate, misleading, defamatory, libelous or in violation of any law.
- 8) Do not post any statement, ask questions or use language which may be construed as offensive, harassing, obscene, pornographic, profane, threatening, abusive or invasive of a person's privacy. This includes swear words or abbreviated swear words.
- 9) Do not post any statement that may be construed as discriminatory on the basis of race, gender, sexual orientation, religion or any other form of illegal discrimination.

10) Do not share information or tips that might be used to promote, encourage or support suicide or self-harm.

11) Say goodbye to the other users and the facilitator when leaving the Online Support Group, whether at the end of an online session or earlier. When users leave abruptly, without saying goodbye, it may be distressing to other users who may worry that you have left because something has upset you, especially if you have left the group early.

12) If you believe someone else is behaving or posting inappropriately, please let the facilitator know, and he/she will address the behavior.

Confidentiality: While confidentiality is addressed and respected, if your child participates in the Online Support Group, certain personal information will be disclosed to [REDACTED] and certain information will be collected through the Google platform (governed by Google's privacy policy and terms of use, as noted above). You are aware and agree that the facilitator may take a record of, and retain, your child's personal information such as name, address, telephone number or email address in order to be able to correspond with your child but that the facilitator will not share any personal information with any third parties unless required by law, or unless the facilitator or [REDACTED] needs to take appropriate action in the case of an individual intending to do harm to self or others, if abuse or neglect is suspected, or if illegal activity is suspected or reported.

Medical Disclaimer: You understand that this [REDACTED] Online Support Group does not supply professional medical advice or clinical treatment information, and that any advice or information your child may receive through this Online Support Group is not a substitute for professional medical advice. Individual variances in cancer treatment require the consultation of a qualified physician to make sound medical decisions, and any specific or urgent questions about your child's health should be directed to your child's health care provider.

Disclaimer of Warranties: [REDACTED] and the [REDACTED] Online Support Group makes no warranty or guarantee, either express or implied, regarding the accuracy, completeness, or timeliness of its content, and you will not rely upon any information contained therein as a substitute for consultations with qualified health professionals who are familiar with your child's medical needs. You agree that [REDACTED] is not responsible for, nor will it be liable for, any damage to, or viruses or other disabling code that may infect your computer equipment, software or other property as a result of your child's participation in the Online Support Group or any internet sites to which the Online Support Group contains a link.

Limitation of Liability: The [REDACTED] Online Support Group may contain links to non-[REDACTED] sites over which [REDACTED] has no control or responsibility for content, and that a link to a non-[REDACTED] site does not mean that [REDACTED] endorses that site. You understand that [REDACTED] disclaims any implied representations or warranties about the accuracy, relevance, timeliness, completeness or appropriateness of these or any other sites on the Internet. Trademarks referred to are the property of their respective owners. You agree to hold [REDACTED] its affiliates, officers, directors,

employees and volunteers harmless from any and all claims relating to the Online Support Group and any website to which it is linked.

You agree that [REDACTED] or any of its affiliates, officers, directors, employees and volunteers shall not be liable to you or your child for any loss or injury caused in whole or in part by either negligence or contingencies beyond its control in procuring, compiling, or delivering information to the participants of the Online Support Group. You also agree that in no event will the [REDACTED] Online Support Group or the contributors of information to the Online Support Group be liable to you or anyone else for any decision made or action taken by you or your child in reliance on such information or for any consequential, special or similar damages, even if advised of the possibility of such damages.

By signing below, you are indicating that you have read, understand, and agree to the above terms:

_____	_____	_____
Parent's Signature	Parent's Name (Print)	Date

_____	_____	_____
Participant's Signature	Participant's Name (Print)	Date

This form must be received prior to your child's participation in the Online Support Group.

Forms can be emailed to [REDACTED]

Or mailed to:

Jennifer E. Rupp, BS, CCLS

Child Life Specialist

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Appendix B

Image of Google plus Community Teen Group Page

The screenshot shows a Google+ Community page for "Teens Connecting with Cancer". The page is viewed in a web browser with the address bar showing the URL: <https://plus.google.com/u/0/communities/106401378587455013418>. The page header includes the Google+ logo and the word "Communities".

The community profile on the left shows the name "Teens Connecting with Cancer" and a "MANAGE" button. Below the profile is a search bar and a filter menu with options: "All posts" (checked), "Discussion", "Resources", "Websites", "College Scholarships", and "Guidelines".

The main content area displays several posts:

- A post by Jennifer Rupp (Owner) with the text: "What do you want to share?"
- A post by Jennifer Rupp (Owner) with the text: "I will be 'live' and moderating the group Monday-Friday mid-day in case any one needs anything! I will check on the site on a daily basis to see if you all need anything! Happy Connecting! Shared privately" and a "Add a comment..." button.
- A post by Jennifer Rupp (Owner) with the text: "www.makeawish.org" and an image of a young boy in a suit, with the text: "Make-A-Wish® America" and "We're celebrating 10 years of the before campaign with Macy's. Wish before to Santa and reindeer with Macy's!" and a "WISH AWAY" button.
- A post by Jennifer Rupp (Owner) with the text: "www.flashesofhope.org" and an image of a man and a young boy, with the text: "Flashes of Hope" and "FLASHES OF HOPE" logo.
- A post by Jennifer Rupp (Owner) with the text: "College Scholarships for Childhood Cancer Survivors" and a link to "Ped-Onc Resource Center: <http://www.ped-onc.org/scholarships/index.html>".
- A post by Jennifer Rupp (Owner) with the text: "My College Scholarship" and a link to "mycollegescholarship.org".
- A post by Jennifer Rupp (Owner) with the text: "Welcome!! Please feel free to introduce yourself to the others here on the community as others gradually join! Feel free to share something about yourself or your New Years resolution if you made one!! This group is for you all to get to meet other teens being treated!"

The bottom of the page shows a Windows taskbar with several open applications, including "Teens Connecting with Cancer", "Inbox - Jennifer E. Rupp...", "D:\MC PROD - USB PEET H...", and "CIS Viewer - VRenole". The system clock shows 2:30 PM.

References

- Barak, A., Boniel-Nissim, M. & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior*, 24, 1867-883.
- Barakat, L., Galtieri, L., Szalda, D. & Schwartz, L. (2016). Assessing the psychosocial needs and program preferences of adolescents and young adults with cancer. *Support Cancer Care*, 24, 823-832.
- Barrera, M., Damore-Petingola, S. & Fleming, C., Mayer, J. (2006). Support and intervention groups for adolescents with cancer in two ontario communities. *Cancer Supplement*, 107(7), 1680-1685.
- Best, P., Manktelow, R. & Taylor, B. (2014). Online communication, social media and adolescent wellbeing: a systematic narrative review. *Children and Youth Services Review*, 41, 27-36.
- Botta, A. (2009). Strengths-based group work with children. In Webb, N. (Ed.), *Helping Children and Adolescents with Chronic and Serious Medical Conditions. A Strengths-Based Approach*. (pp. 137-154). Hoboken, NJ: John Wiley & Sons, Inc.
- Davis, K. (2013). Young people's digital lives: the impact of interpersonal relationships and Digital media use on adolescents' sense of identity. *Computers in Human Behavior*, 29, 2281-2293.
- Elwell, L., Grogran, S. & Coulson, N. (2012). Adolescents living with cancer. the role of computer-mediated support groups. *Journal of Health Psychology*, 16(2), 236-248.
- Fukkink, R. & Hermanns, J. (2009). Children's experiences with chat support and telephone Supprt. *Journal of Child Psychology and Psychiatry*. 50(6), 759-766.
- Hicks, M. & Davitt, K. (2009). Chronic illness and rehabilitation. In Thompson, R. (Ed.), *The Handbook of Child Life a Guide for Pediatric Psychosocial Care*. (pp.257-286) Springfield, IL: Charles C. Thomas.
- Hunt, M. (2014). How teens can benefit from online support groups. (Blog post) Retrieved from www.counselingondemand.com
- Kohut, A., LeBlanc, C., O'Leary, K., McPherson, AC., Nguyen, C., McCarthy, E. & Stinson, J.

- (2017). The internet as a source of social support for youth with chronic conditions: a Qualitative study. *Child: Care, Health & Development*. 44(2), 212-220.
- Leung, C. (2017). Assessing the mobile phone dependency and teens' everyday life in Hong Kong. *Australian Journal of Psychology*. 69, 29-38.
- Lightfoot, C., Cole, M. & Cole, S. (2013). *The Development of Children*. (7th ed). New York, NY: Worth Publishers.
- Mariecel, P. & Delaet, D. (2015). Health risk behaviours in adolescents and young adults with special health care needs. *Pediatrics*. 27(1). 132-137.
- National Cancer Institute. Retrieved on 2/28/18 from www.cancer.gov
- Nylander, C. Seidel, C. & Tindberg, Y. (2013). The triply troubled teenager-chronic conditions associated with fewer protective factors and clustered risk behaviours. *Nurturing the Child*. 103(2). 194-200.
- Official Documents of the Child Life Council. (2011). Arlington, VA. Child Life Council.
- Savage, T. (2005). Ethical, Moral, and Legal Issues in Children's Health Care. In Rollins, J., Bolig, R. & Mahan, C. (Ed.) *Meeting Children's Psychosocial Needs across the Health-Care Continuum*. (pp. 455-491). Austin, TX: Pro-ed.
- Subrahmanyam, K. and Greenfield, P. (2008). Online communication and adolescent Relationships. *Future of Children*. 18(1). 119-146.
- Understanding Group Therapy. Retrieved on 2/28/18 from www.apa.org
- Valkenburg, P. & Peter, J. (2011). Online communication among adolescents: an integrated model of its attraction, opportunities, and risks. *Journal of Adolescent Health*. 48, 121-127.
- Zelikovsky, N. & Petrongolo, J. (2013). Utilizing peer mentors for adolescents with chronic Health conditions: potential benefits and complications. *Pediatric Transplantation*, 17, 589-591.

