

**Outcomes and Processes of a Camp for Youth with Cancer**  
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**Introduction**

As part of Camp For All's ongoing commitment to evaluating its program, Camp Periwinkle was chosen as the focus of a case study during the summer of 2009. Camp Periwinkle was chosen because of its long-standing association with Camp For All (CFA), its willingness to participate in an evaluative case study, and involvement of the lead researcher of this portion of the study (Ann Gillard) in the overall CFA program evaluation since 2007.

In 2007, an initial assessment was undertaken in which four partner camps of CFA (including Camp Periwinkle) were evaluated to understand outcomes associated with camp participation. The results of this evaluation were used to develop and implement pre-, post-, and follow-up questionnaires for campers in 2008. While the outcomes that were identified were relevant to CFA as a whole, it also appeared that there were qualitative differences between partner camps, and additional questions were generated about the outcomes of camp for youth, and the processes by which they occurred.

The purpose of this study was to understand how participation at a barrier-free camp serves as a developmental support for young people with cancer. Specifically, this study addressed the following research questions: (1) what are the outcomes of participation in camp; and (2) what are the processes that facilitate those outcomes?

**Rationale for Project**

Like all young people, youth with chronic illness face many psychosocial tasks necessary for their well-being and transitions towards adulthood. Some specific issues faced by youth with chronic illness include coping with feelings of isolation and restrictiveness, and integrating the effects of the disease into various contexts of their lives. For example, youth with chronic illness often need to plan for debilitating medical treatments such as chemotherapy, and may miss school (and related socialization opportunities) for several weeks or months. The development of relationships with others can be impacted by chronic illness as well, and includes the tasks of establishing supportive connections with others as well as making decisions about discussing their conditions. Even when physical health issues are successfully managed, there may continue to be social or emotional challenges for youth with chronic illness.

One context of support for the positive development of youth with chronic illness is out-of-school programs such as summer camp. During participation in camp programs, youth can be exposed to support for developmental processes such as emotional regulation and peer relationship-building, opportunities to explore emerging identities and interests, and for youth to become empowered and build character, skills, and relationships (Henderson, Bialeschki, & James, 2007). Specifically, camps serving youth with chronic illness tend to understand the importance of providing their campers with such opportunities because many of their campers do not have optimal supports to experience these outcomes in their daily lives. Recognizing the strengths of the camp experience, professionals serving youth with disabilities have advocated that this population stands to greatly benefit from camp participation (e.g., Bluebond-Langner, Perkel, & Goertzel, 1991; Brown, 2005; McAuliffe-Fogarty, Ramsing, & Hill, 2007). Understanding how particular programmatic inputs optimize outcomes is a key step in the design

and implementation of quality recreation-based programs that support youth development for those facing additional challenges as they grow.

### **Methods**

Camp Periwinkle, CFA, and Clifton Watts met via a phone conference with Ann Gillard in spring 2009 to establish research questions and study procedures. Consensus was achieved, and Dr. Gillard attended Camp Periwinkle from August 1-7, 2009 as an assistant counselor with minimal cabin duties. Her primary purpose at camp was to interview campers and staff, and conduct unstructured observations of various camp activities.

An interpretive case study framework was used to investigate the research questions (Yin, 2003). The case was a week-long camp for 182 youth with cancer and siblings ages 6-15. Data in 2009 were gathered through interviews with 10 campers ages 12-14 who had or previously had cancer, 10 adult staff members (Periwinkle administrators, activity specialists, medical staff, and counselors), 4 junior counselors (former campers and cancer patients); unstructured participant observations conducted during camp; and artifact review.

An original goal of the study was to interview patient and sibling pairs in order to compare and contrast answers to the research questions from these different populations. However, because only 53 campers had consent to participate in the study, matched pairs in the appropriate age range were not available. In order to maintain consistency of data, only campers with cancer were selected to participate in interviews. Additionally, many of the younger campers with consent to participate in the study provided sparse answers and insights into the outcomes and processes of camp. Therefore, four Junior Counselors (ages 18-20) who were former campers were chosen to provide more detailed interviews.

Additional data from a related study in 2007 were analyzed, and consisted of 3 focus groups with a total of 9 staff members, and 6 focus groups with a total of 21 campers. Observational data came from unstructured and informal observations in the cabin and activity areas, and during all-camp events. Additionally, “artifacts” in the form of staff manuals, websites, meeting agendas and notes, and gifts (t-shirts, medals, etc.) were observed and examined. Please see Figure 1 for a summary of data sources.

Interview and observational data were transcribed, coded, and organized according to the two guiding research questions in an iterative process using Atlas.ti qualitative data analysis software. Themes were developed that were grounded in the data and related to the research questions. The process of constant comparison was used to ensure that different data sources reflected themes that converged onto the research questions. The themes discussed below emerged because they were reflected in data from all sources. Throughout the study, several steps were taken to assure validity and reliability. These steps included collecting multiple sources of evidence (interviews and observations; campers and staff), constant monitoring of potential researcher bias, and member checks with the Camp Periwinkle Executive Director and Board members.

Figure 1. *Data sources.*

| <b>Data Collection Site</b>      | <b>Individual and focus group interviews with campers</b> | <b>Individual and focus group interviews with staff</b>  | <b>Individual Interviews with Junior Counselors</b> | <b>Observations</b>   |
|----------------------------------|---|--|---|---|
| July, 2007 Camp Periwinkle (CFA) | 6 focus groups with 21 youth ages 10-15                   | 1 formal interview with camp director;<br>3 focus group interviews with 9 staff members  | None  | Informal, 10-20 minutes in dining hall and activity areas (3 people at 2 activities each)           |
| July, 2009 Camp Periwinkle (CFA) | 10 individual interviews with campers ages 12-15          | 2 formal interviews with counselors;<br>1 focus group interview with 3 health care professionals;<br>1 focus group interview with 3 arts & crafts specialists;<br>Informal discussions with 2 Periwinkle staff | 4   | Participant observations in an assistant counselor role, artifact review, unstructured observations |
| <b>Total:</b>                    | <b>31 campers</b>   | <b>20 staff</b>  | <b>4</b>  | <b>7 days as participant observer</b>   |

### **Findings**

The findings from the Camp Periwinkle case study are organized according to research question. Following the brief outline below are quotations and context for each of the themes and sub-themes.

1. *Research Question 1: What are the outcomes of participation in camp?*
  - a. Connection to a caring community
    - i. Desire to maintain involvement with camp and pride in length of involvement
    - ii. Dedication to common goals
  - b. Feeling of reprieve
    - i. Freedom and escape
    - ii. Striking a balance in life between “just being a kid” and managing difficult cancer issues
    - iii. Feelings of flow, involvement, and engagement
  - c. Increased positive attitudes.
    - i. Increased extraversion and socialization skills
    - ii. Perseverance and confidence
    - iii. Awareness of ability to exert autonomy
    - iv. Feelings of gratitude and appreciation

2. *Research Question 2: What are the processes that facilitate those outcomes?*
  - a. Spatial and social proximity to others
  - b. Full accommodation for campers
    - i. Integrated and accessible facilities and activities
    - ii. Opportunities to be physically active.
  - c. A habitat of fun
    - i. Abundance
    - ii. Opportunities for transgressions

### **Research Question 1: What are the outcomes of participation in camp?**

#### **Theme 1: Connection to a Caring Community**

The social norms in camp emphasized caring, which was evidenced through listening, treating campers as capable, providing sympathy, and creating closeness. Many campers discussed how appreciative they were of the counselors giving their time to come to camp: “They want to bond with you too, they’re not just here to get credit for a college course or something like that. They’re here to be with you,” (focus group participant). Campers also discussed the high levels of caring they received from their counselors: “They don’t look at you like you’re a cancer patient, they look at you like you’re a person. They don’t give you that pity. (Does that help you?) It does make me feel better about myself,” (focus group participant). A Junior Counselor explained what it was about camp that made her feel cared for:

And it was great for someone to always listen to me and to believe everything I said. Like if I was tired: here’s a Gatorade, take a nap. Like it was fine, there were no worries about it, it was just everything I wanted to do. The counselors were ALWAYS fun and energetic and wanted to make sure you were feeling good and wanted to make sure you were having fun. It was the most important things all the time. You would think that at such a big camp some kids would fall to the back, if they’re quiet. But no, every single kid was made to feel unbelievably special in their own way and their own right. Whether sibling or patient, finished treatment, in treatment, everyone’s made to feel special, like the carnivals and the morning aerobics, and every activity.

Observational data also supported the theme that counselors cared for campers. For example, at the dances, counselors would move around the perimeter of the dance floor and invite shy “wallflower” campers to dance, and were almost always successful. For many of these shy campers, it was the first time that anyone had asked them to dance.

Campers cared for each other in many ways, especially as noted by staff members. For example, a counselor shared a story of one girl who was very ill: “But all week long the girls rallied, she was sick, having breathing treatments, they all did her hair, she went to the dance for one song, so weak, went back and rested. It was magical to see them do that for her, and the time that she had.” An arts and crafts director shared the story of some boys who donned pirate eye patches in solidarity with another boy who had sustained an eye injury during camp.

A caring community was also evidenced by the special bonds that emerge between people experiencing cancer. A Junior Counselor shared that:

Friends at home don’t really understand the whole bond between two cancer patients I guess. It’s there because you went through it together and you know

what it's like. And a friend at home doesn't truly understand how the hospital works and how chemo works and how the IV pole works. But the camp friends do.

Another Junior Counselor explained bonding in a more general sense:

It's unique because it's a community, like you come back and you recognize your counselors, you recognize your friends, you meet new friends. What does a community feel like? It's all love. And everyone embraces everybody. Half the time you'll be walking around and saying hi to people you don't even know. And it's just being able to feel, to feel love, you really can.

### Theme 1, Sub-theme 1: Desire to maintain involvement with camp and pride in length of involvement

At Camp Periwinkle, it was clearly evident that participants (campers and counselors) felt part of a phenomenon with a past and a future. For example, a DVD film of the previous year is made each year and given to potential participants, viewed by past participants, and shown on the first night of camp. This helped people reflect on past experiences through shared collective memory, and inspired people to make the camp experience even better in the future. Importantly, there was no sense that previous summers were compared as either inferior or superior to the present summer. Rather, the videos seemed to spark creative solutions to camp activities that could be made better, and for new activities. Additionally, several efforts were made to create films, songs, and other artifacts that would be seen in the future, such as cabin videos and crafts.

A strong value in the Camp Periwinkle community is length of involvement. For example, during staff training, people cheered the loudest for those who were sharing that they had been involved for over 20 years. A health care staff member shared more about this value:

I think it's a lot of the camaraderie; it's very tight, the camaraderie amongst the group of us who come here the day before everyone gets here. We've all been doing this forever. Each year has incredible emotional impact on ALL of us. We've all done this work. On average, people have probably been here 10 years. And many many more years than that. Each year you take something for yourself from it. It's huge.

Another health care staff member expanded on this idea:

I think when you live this closely with people for a week, we've all known each other forever and there are a lot of people here who've known each other forever, you just continue these really tight relationships from the previous year and it never feels like it's been a year since you've last been together.

A third health care staff member described the long-lasting bonds between campers who attended Camp Periwinkle: "They talk about it and they want to come back, and the numbers have grown in the past few years exponentially because they feel this sense of acceptance and camaraderie... They're really using this as a kind of connection to each other, and to becoming young adults."

### Theme 1, Sub-theme 2: Dedication to common goals

There was a strong ethos of focus on the enjoyment of campers. For example, in staff training, a director stated very clearly, "We're here for the campers. Our job is to focus on campers. If you do that, at end of week you will say you had a great experience... This week is supposed to be THE BEST week of these kids' lives." Put into context, a health care staff

member explained why this was so important: “camp is often sometimes, the last experience a kid’s gonna have before they lose the fight. So, one of the better places to be at besides with your family is to create new friends and experiences before that day comes.”

These messages were also perceived by the campers. For example, a male camper shared about the counselors: “I feel like they’re part of my family because they treat you really cool. They’re always making sure you’re all right, and always try to make you have fun. And even if you don’t want to do something, they try to put fun into it.” Additionally, campers were aware that the camp staff provided for their needs. A Junior Counselor explained that “your physical needs are taken care of, your fun is taken care of.”

A staff member focus group participant described the shared vision of camp:

The hospital takes care of the physical and the medical needs, but the emotional and psychological needs, which are a lot of time ignored in the hospital, need to be met in a different arena and I think that’s what Camp For All provides in the activities in the fact that they can do them, they can all participate in them, they don’t have to be left out or limited, makes them feel that good so I think that’s the reason we come here because it meets our needs for the physically and mentally challenged that they can participate in all these programs and get a rewarding experience out of it, which is what the whole mission of our foundation is.

There were several specific ways that evidenced the shared goals of camp. Observations during meal times in the dining hall resulted in data that reflected counselors’ deference to campers. If a camper joined the end of the cafeteria line, a counselor would typically invite the camper to go ahead. Counselors would open doors for campers in a chivalrous fashion. When a counselor would pass a camper, the counselor would typically give the camper a high five or a smile.

## **Theme 2: Campers Experienced Reprieve.**

Reprieve was achieved through feelings of freedom and escape, striking a balance in life between “just being a kid” and managing difficult cancer issues, and feelings of flow, involvement, and engagement.

### Theme 2, Sub-theme 1: Feelings of freedom and escape

Feelings of freedom and escape were especially important for this population because of the stresses of cancer treatments. A Junior Counselor explained “They’re free, they’re more free than in the hospital. (What are they free to do here?) They’re free to run around, they’re free to get outside and have some fresh air, they’re free from the IV pole, free to have fun I guess.” Several campers discussed feelings of freedom and escape from their families:” Relax and spend time away from my family. I get to relax and not have to worry about my brother.” A focus group participant shared that “I think this place is like a home away from home for all of us, like, a haven.” A Junior Counselor explained her role in helping campers feel freedom:

My job here is to make sure these kids are as much kids as they possibly can be and that they DON’T have to grow up at all, that they can be silly and goofy and talk loud and cheer. Like when we went to Horseshoe Junction, they were being all loud on the bus and I remember being ‘oh we should tell them to be quiet, the bus driver [might get mad].’ And I’m like wait, they don’t ever get a chance to do this. Let them cheer, let them sing along.

## Theme 2, Sub-theme 2: Striking a balance in life between “just being a kid” and managing difficult cancer issues

A health care staff member described how camp helped campers to gain perspective:  
I think it’s just a really big safe zone. You don’t have to worry that you have enough money to pay the bills, you don’t have to worry about your parents worried about you, you don’t have to worry about homework, you don’t have to worry about arguments. Sort of, all that daily stress we all deal with...it’s a huge getaway.

Another health care staff member shared a heartbreaking story of a boy who was very ill:  
It was movie night, and he was sitting with me at the movie and he looked at me and he had all these tumors pop up along his neck and his jaw, and he goes “Dr., are these tumors? Do I need to worry about this?” and I said “Nope! This is camp so we don’t need to worry about anything.” And he just put his head in my lap and he just fell asleep.

A third care staff member shared that “I think it’s a protected environment for them and lets them close the world to all the badness that’s going on around them. Especially if kids are near the end.” Throughout camp, several campers were advised by counselors and other campers to relax, just have fun, and to be a kid.

## Theme 2, Sub-theme 3: Feelings of flow, involvement, and engagement

Throughout camper and staff interviews and observations, it was clear that a major purpose of camp was to have campers put their illness to the back of their minds. Due to the tightly scheduled days, constant activity, and high levels of excitement, campers were often too busy to focus on the negative aspects of campers. Rather, cancer was intentionally situated as something to deemphasize for a week. A health care staff member shared that

It’s just part of a daily routine that they’re doing right now. Right now the focus is on for you to have fun and do whatever you want to do to be a kid. In the meantime we’ll take the break to get your central line flushed or take your medication. But that’s just part of our daily routine, but other than that we’re going to have fun, go on ropes courses, the pool, horseback, mountain biking.

A staff focus group participant shared that while getting a spinal tap, one camper discussed his counselor: ““He’s the coolest guy ever! We like played ball the whole time and I forgot I had cancer.”” Activities in camp were designed to be fully engaging. For example, the Winter Olympics provided opportunities for high levels of involvement, some more than others. Those activities that provided the most involvement, flow, and engagement were those that had fewer rules, more randomness, more messiness, and less emphasis on skill or luck to succeed, such as the water fight game.

### **Theme 3: Increased Positive Attitudes**

Campers developed: Increased extraversion and socialization skills, perseverance and confidence, awareness of ability to exert autonomy, and feelings of gratitude and appreciation.

## Theme 3, Sub-theme 1: Increasing extraversion and socialization skills

These outcomes were frequently mentioned by campers and staff, and observed. In nearly every staff interview, staff members would discuss specific examples of campers they knew who

came to camp quiet and shy, but left camp laughing and hugging others. A Junior Counselor shared her experience:

I was super nervous and shy 'cause I was bald - being a girl and bald it does not work that well! But she made me come and it was the BEST thing that could have ever happened to me. After I left camp I wasn't shy.

Staff members who interacted with campers in the hospital also noted that campers would frequently return from camp and maintain their higher levels of extraversion in the hospital setting, especially with other youth who had not been to camp.

Camp also seemed to influence the outcome of socialization over time, as one camper shared how he had changed over the years: "A lot more open to talking to people and stuff. I used to be really shy when I first came here - you can ask any of my old counselors that." A Junior Counselor reflected

It definitely pulled me out of my shell because I was a pretty shy guy and then once I came here honestly it was kinda a turning point, the dances got me out of my shell. I never really danced as wild and crazy and as non-caring what people thought of me as I did when I got to camp, and that's the honest truth... At the time, I was off treatment, so I guess it made me come out of my shell. So when I went back to school the following fall after camp I was more open about things, I talked more, I guess I was louder, I made more friends when I went back to school. I guess I can thank camp for that.

The increase in extraversion and socialization was especially important for campers with cancer because many had lost friends or become more distant from old friends because of illness due to treatment and missing school. Camp provided additional opportunities to make new friends.

### Theme 3, Sub-theme 2: Development of perseverance and confidence

A camper focus group participant explained his feelings about camp, "I think it makes you more confident with yourself. You can do things even if you have a disability. I think it just gives you more self-confidence in yourself." A Junior Counselor explained how she developed confidence at camp:

At camp they go swimming every day and I didn't like going in the pool because I was overweight from the steroids but it wasn't a big deal. Glamour shots - not concerned about anything. I have a scar from my port of cath that always freaked me out wearing tank tops so it's no issue at camp and it gave me a lot of confidence back and it gave me a lot of courage to continue fighting and to know that being sick, it's not the best thing in the world, but it's not the worst if you look at it the right way.

The ropes course was frequently cited as a location for the development of these outcomes. A staff focus group participant shared that:

I think they take a sense of independence. For some of these people, they're very sheltered and they're parents don't let them do anything and they're climbing rock walls and going down zip lines and the fact is that they're overcoming their fears and obstacles. Which, here, the rock wall is high but there's no way you're going to fall off and hurt yourself but in real life there's more challenges and things that are more difficult, but if you start with the easy stuff and you build yourself up you can face those more difficult challenges of being ostracized because they're different, having to go through chemotherapy, if you can start with the small



things and conquer those I think it gives you confidence to move through those more difficult challenges and obstacles.

A counselor explained that

The ropes course changes people's lives who have missing limbs or are so sick, and they work it, and they're so cheered on, and they do that zip line. When they see the pictures, the parents say 'He never would have done that. He wouldn't have. Is that my kid?' and the kids come home and the parents call and say 'I can't get my kid to stop crying 'cause he wants to live at camp.'

There were strong consistencies between what staff and campers discussed about increasing confidence and perseverance, and they often used similar wording. Confidence was gained by persevering through challenges, which seemed to carry over to other situations that required successful coping skills, such as enduring painful cancer treatments.

### Theme 3, Sub-theme 3: Campers' awareness of their abilities to exert autonomy

At home, campers were typically coddled, and deterred from engaging in many activities, especially risky and social activities. A focus group participant explained that camp was "An opportunity to get away from home and do stuff that you usually aren't allowed to do at home." Another focus group participant discussed how at camp he used fewer excuses to refrain from participating in activities: "You mean do we play the cancer card here? Yes, yes we do. We tell the counselors to get us drinks. [But] I haven't done that in a while." Campers discussed how counselors treated them: "They're not over protective. If something's wrong they'll be like 'Well, do you want to do this or go here?' They give you a choice." This encouraged campers who had physical limitations to become independent: "I like the pool because that's the only where we can be totally independent. I can swim, I can walk in the pool. It's cool 'cause I can be totally independent in the pool."

Health care staff had a more thorough understanding of why this outcome was so important in campers' lives:

Typically, in the hospital, they regress and they get very used to having everything done for them. Moms will give me this whole list, 'Well they take their medicine, it has to be broken into pieces and mixed with this' and at the end of the week I'm like 'What happened to so-and-so' and you ask their counselor and they're like they watch all the other kids just gulp their medicine down and so they just start doing it. Even some things as typical as something as that, they just kind of grow back up a little bit and catch back up to their more level age group instead of going backwards.

### Theme 3, Sub-theme 4: Gratitude and appreciation

A Junior Counselor shared that the camp experience developed appreciation in her:

Once I did see how great it was and how great I would survive and how blessed I am, I think it did mature me a lot more in a sense. From an early age I knew I wanted to be in the medical field and help others and come back to this camp and do stuff. I knew I wanted to do that, and go to school for. I learned that I can't take life for granted. I think it did mature me and make me realize how important life was and how it can change very fast and be affected very fast.

Campers gained appreciation as they compared themselves to others as well: “I see so many different things here, like if it’s cultures or kids that have had worse than you. It makes you appreciate what you’ve had.” A Junior Counselor explained how she developed compassion:

Like to not take anything for granted, like not saying hurtful words...have more care and compassion in everything you say and everything you do because every moment of your life is important. At the other camp, there’s a saying that you only live once. And that’s an amazing motto because it’s so true.

Staff and campers also indicated that feelings of appreciation and gratitude encouraged them to “pay it forward” by planning to return to camp to help, enter into a helping profession, and/or applying care to their interpersonal relationships. An adult counselor who had had childhood cancer and worked at Camp Periwinkle for many years shared that he strove to “Really have a good time no matter where I went because I had everything taken away for a while and it was brought back and it just was something I didn’t want to throw away, take for granted.” Camp provides youth with opportunities to increase their positive attitudes toward life through the social proximity, exposure to long-term survivors, and appreciation of the good things in life, which carried over into other life domains.

## **Research Question 2: What are the processes that facilitate those outcomes?**

The previous outcomes were influenced by several camp processes: spatial and social proximity to others, full accommodation for campers, and a habitat of fun.

### **Theme 1: Spatial and social proximity to others**

Living in an intentional community for one week, people at camp engaged in cooperative living efforts in close physical proximity. Outside of camp, it is typically uncommon to see youth with visible effects of cancer, such as missing limbs or baldness. Being in the presence of other people who were bald, missing limbs, or spent time at the cancer hospital was comforting and a means to improve self-regard as well as social connections. Especially, campers were exposed (especially by the health care staff) to older youth and counselors who were long-term survivors of cancer, and this provided hope and encouragement. An arts and crafts director shared that “We live in very close quarters. And granted it is really only a week. But a lot of really intense things happen. I think [another director] referred to it as an Olympiad. The people that are sort of at your side in those kinds of things are occurring.”

Baldness was a trait that was often considered. A Junior Counselor discussed how baldness was understood by campers:

Some of the girls will get off [the bus] wearing wigs. And they see other kids. They’re not around other children with cancer, right? Maybe in clinic, but that’s very very different. And they’ve been made fun of in school, and people just stare at them in public. And they get here and they see other children wearing do-rags, but at the pool they see the bald kids. And by the end of the week...I’ve only had one kid who has not taken off their wig. And being a kid again, and feeling that acceptance I think is tremendous for their self esteem.

Discussing the ways that camp is different than life at home, a Junior Counselor explained that at home,

You aren't surrounded by people who are going through the same things you are and you're around a whole group of kids who are all normal and your age and they just don't understand what you've gone through, what you're going through, why you might fall, or have an amputation. I feel like this camp has a lot of support in that and that they all can understand, or even as a sibling understand what you're going through in your life. So I feel it's more different in that sense.

As a result, a health care staff member explained that campers "Don't have a pity party for themselves any more 'cause they see other kids that way. Just 'poor me, I have no hair.' They come here and some of the little ones they lost their hair and stuff and they're doing whatever.

However, social proximity can also be related to negative feelings. A Junior Counselor described an interaction she overheard with another counselors and a young camper.

This little girl the other day was crying to this other counselor "Hey I don't like how they say 'I made it, I'm the world's greatest' [i.e., "World's Greatest" by R. Kelly]. It makes me sad." The counselor was like 'why? You made it! You are the world's greatest.' But she was like 'Some kids DON'T make it.' And she's only 8 years old, and it's amazing that she can be so young and understand something like that.

More often however, feelings of social proximity tended to unite campers. A staff focus group participant explained how camp opportunities for bonding influenced camper outcomes:

You see people with similarities. All these things bring out a chance for them to bond together and, like you said, I think a lot of it is doing everything together and having chants and cheers that you do in your group and do things with your group, like raiding the candy in the chow hall that you come together as a team, all those things build a team spirit, once you have a team spirit even those outliers or those shy people who are on the fringes get drawn in and then everybody becomes one unit and functions together, they talk together, they open up more.

## **Theme 2: Full accommodation**

"Full accommodation" was evidenced by: integrated and accessible facilities and activities and opportunities to be physically active. Camp provided a culture of ensuring that all campers were warmly encouraged to expand their beliefs about what they could do.

### Theme 2, Sub-theme 1: Integrated and accessible facilities and activities

The facilities philosophy of Camp For All is that is "barrier-free." Camp Periwinkle medical staff members are well-aware of the health needs of individual campers, and ensure that appropriate staff and equipment are on hand to facilitate their participation in camp. Staff members pride themselves on being able to accommodate nearly every camper. For example, a health care staff member shared the story of a young boy with a kidney tumor:

He was my patient, and he was not in good shape. And his parents brought him up...and taking him around on the golf cart to show him what he could do, and what might be dangerous; well, he could do this blob thing where he jumps on this thing, but that could rupture one of his tumors and that could make him really sick and even possibly cause him to die. And [his parents] said 'HE wants to go to camp and HE wants to do what he wants to do, so he needs to be able to do that.' And he did *everything*.

A counselor explained how the equipment and facilities promoted participation, which was in contrast to campers being constrained at home:

They make the wall so everybody can do it, they make sure everybody can get in the pool, everybody can participate. Even if it's in the bikes, they have special bikes everybody can use. You're all together in a unit, like all together doing stuff together. You're not being ostracized or being put off.

“Challenge By Choice” is a programming philosophy used by CFA and Camp Periwinkle, and was described by counselor:

I think the big thing is it's your choice if you want to do anything. And you have the ability to do whatever you want. As we go to each activity, they're not gonna force you to do anything you don't want to do, but if you want to do it, you can do, you will be able to do it, you'll be able to find some level of satisfaction that you completed the task that we're working on at that time.

Compared to limitations faced at home, at camp it was easy to participate in activities and daily living. A health care staff member explained that “When they're at home they're trying to take them to the grocery store, trying to take them here, trying to take them there, they know that it's not really a safe environment for them because of [germs] or something like that. They know here they're safe.”

In some facilities, “accessible” means separate but unequal. For example some facilities place one wheelchair-accessible restroom a long distance from the main gathering areas. At CFA, all bathrooms are accessible to everyone and are located in or very near to locations where campers converge. At CFA, accessibility was not made to be a big deal, was treated discreetly, and easily blended into the facility design and activity instructions. Another form of accessibility was the provision of clothing, bedding, and other supplies to campers financially unable to provide for their own. Additionally, approximately 20 golf carts were brought to CFA by Camp Periwinkle due to the high numbers of campers who get fatigued.

### Theme 2, Sub-theme 2: Opportunities to be physically active

Camp provided many opportunities to be physically active at camp instead of being more sedentary at home. This was especially mentioned by campers in their interviews. One camper explained that camp was different from home

Because it's stressful because you can't do everything everybody else can do, even though you kind of have to. You just need a break. Like it's easier for other people to get stuff done because I fatigue really fast, and here, it doesn't really matter, they'll like, wait up for ya. [Do you still get fatigued here?] Yeah, but it's not as bad.

Another camper shared that it's easier to do activities at camp because “people don't really care what you look like when you're doing it.” Another focus group participant explained that he learned from camp that “Even if you're going through chemo you can still do stuff.”

### **Theme 3: “A habitat of fun”**

This habitat consisted of abundance and opportunities for transgressions, which were grounded in an unceasing focus on campers' enjoyment and engagement. A Junior Counselor described what made camp special:

I think it's unique because you're in a setting with so many kids and you're in a setting where you're scheduled to have fun constantly and you don't have as much

down time as at home so it creates a habitat of fun and constantly going that you don't get anywhere else.

### Theme 3, Sub-theme 1: Abundance

The theme of Camp Periwinkle in 2009 was "More than you can imagine." This theme of abundance was evidenced in multiple ways, such as with prizes and gifts during the Carnival event, food, and numbers of staff members. When asked what had changed about Camp Periwinkle over 25 years, a long-term staff member replied "more, and better." A counselor shared about a girl in her cabin:

One girl in there is like 'I've never got so many SHIRTS!' It's excess, it's eat as much as you want. Some of these kids don't get a full meal, or maybe they get free lunches at school. It's really, with boundaries, from the standpoint of fun, there's not cap to how much fun you can have.

Field notes taken during the Carnival event described it as "Sensory overload, smell of cotton candy, taste of snow cones, glittery prizes, sounds of Brazilian music and fans, so many prizes – a riot of color." A Junior Counselor explained other efforts at creating a feeling of abundance for campers:

It's hard to put into words, it's just amazing, heartwarming, swelling feeling. And it's hard to say on paper, seeing a kid smile, just HOW much that means. Like little activities of going to the pool or making a cabin video and feeling like a movie star. That makes them feel awesome and incredible and people have big lists of things I want to accomplish in my life and you can accomplish those, through imagination and little things. Like people say I want to be a movie star, well make a video and you're your own movie star. And Camp Periwinkle does it all.

### Theme 3, Sub-theme 2: Transgressions

Another sub-theme of a habitat of fun was the opportunity to transgress camp rules, especially through the use of the "Chow Hall Challenge." A health care staff member described this camp tradition:

We call it Chow Hall Challenge because it used to be set up in the chow hall. We literally had lasers and smoke so you could see the laser beams, the beams would come down to the box and you'd have to sneak in, and the police ready to arrest them. So the challenge was to get the candy and run out without being caught and of course we would never catch them because what would we do with them? So we made it a challenge, could they get the candy without us catching them? And it was in the chow hall, hence the name and it's a challenge - can you get by [the directors]?

The Chow Hall Challenge served as a teambuilding opportunity for cabins, and provided a sense of exhilaration and healthy risk taking for campers.

One of the counselors in an older girls' cabin brought to camp fake vomit and a fart machine to play tricks on people in the cabin and in neighboring cabins, and these transgressive jokes were well-received by the campers. Often, the counselors modeled ways to transgress rules in camp, such as advising a group to go after another group during an obstacle course in order to be able to observe the other team's strategy. Still, counselors placed boundaries on transgressions, such as drawing limits at invading individuals' personal spaces. Being able to

transgress rules provided campers with an opportunity to exert autonomy and challenge, which was especially important for those whose lives were tightly regulated and controlled because of their illnesses.

A staff focus group participant summarized what it was about camp that made it so special:

I think it's probably a combination of the atmosphere, the fact that you're there together and the fact that the counselors at this camp are very into camp, they're participating in everything and doing things, the staff here is always into things. I think all of that thing, it just naturally comes together. Kids want to be part of a group, they want to have an identity, they want to have something they can say 'This is mine and these people care about me and this is where belong, this is where I fit in' so I think some of that comes just naturally being divided into cabins, but a lot of it is just the atmosphere and the environment and the people that are around them.

### **Applications and Recommendations**

The findings of this study suggest several recommendations for Camp Periwinkle to consider in future strategic planning efforts in order to optimize outcomes for campers.

1. Camp administrators are urged to strategically plan for opportunities for campers to share concerns and issues about cancer, particularly during informal time in cabins, such as by training counselors to facilitate the inevitable discussions. These discussions emerged, yet some counselors appeared to feel ill-equipped to handle these out-of-the-blue questions and discussions, especially if the counselors were not medical professionals. While formal education workshops about cancer are not necessary or appropriate to the goals of camp, more attention could be paid to the informal opportunities for staff to support campers in discovering meanings in their lives. For example, nightly debriefing sessions about the activities of the day could be conducted by counselors in the cabins before bedtime. This could be followed by one or two developmentally appropriate guided questions that could be answered verbally or by journaling or artistically (i.e. what does camp mean to you? What is a challenge you are working on overcoming?).
2. Camp should provide structured and facilitated activities so that campers can reflect on their challenges and successes in camp and in life. Given that campers increased their positive attitudes, perseverance, feelings of freedom, and socialization skills, camp could provide more intentional and structured opportunities for campers to reflect on the changes in their lives, especially for older and returning campers. This would further reinforce and strengthen the outcomes that campers develop.
3. Special consideration should be paid to activities that are only offered to boys or girls. For example, one older girl expressed dismay that she would not be able to play sports in the safe and supportive environment of camp; at her school, she was frequently made fun of for her weight and had been looking forward to the opportunity to try accessible sports at CFA. Camp administrators may consider providing more choices among opportunities that can promote the positive development of all youth, such as offering a variety of

expressive arts activities to boys and sports programming to girls. For example, if some girls are not interested in putting on makeup, there could be alternate games or activities.

4. Finally, camp should consider strategies to extend the power of a one-week camp session into campers' lives throughout the rest of the year. While many health care staff members mentioned interacting with campers in the hospitals or clinics, there appeared few opportunities for campers to reunite after camp outside of chance encounters (except for Camp YOLO for older campers). Perhaps camp could offer gatherings for campers such as at a basketball game, picnic, or other events in the Houston area. This would provide campers with more opportunities for positive social interactions, and could increase their feelings of hope and perseverance throughout the year.

Because of camp, youth with cancer more effectively negotiate the additional hurdles that often challenge their development. Because of camp, youth with cancer can experience activities and relationships that their healthy peers may take for granted. Because of camp, youth with cancer can experience respite and reprieve from their stressful lives in order to gain deeper and broader perspectives on the meanings of cancer, camp, and dreams. Because of camp, youth can emotionally and socially heal.

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