

# Childhood Cancer Camps and Body Image in Children with Cancer

By Stephanie Jorgensen

## Body Image

What is body image?

- ❖ Body image is a subjective picture of one's own physical appearance established both by self-observation and by noting the reactions of others.
- ❖ Body image is established by age 6. By this age, children are aware of their appearance and people's bias views against other people with certain body types.
- ❖ Adolescence is a very vulnerable period of development because of the significant physical and emotional changes. During this stage in life they increase their focus on physical appearance. How they view their physical appearance affects self-esteem and their psychosocial functioning.
- ❖ Cancer treatment can cause body altering side effects such as:
  - Hair loss
  - Weight gain/loss
  - Physical disfigurement
  - Acne
  - Scarring
  - Skin discoloration
  - Nail changes
  - Presence of central venous catheters
- ❖ According the Erikson's developmental stages
  - Children ages 6-12 are in the industry vs. inferiority stage where they are developing school skills.

- Children ages 12-20 are in the identity vs. role confusion stage where they are forming their peer group and developing a sense of identity.
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One study was done to understand the perceptions of children (ages 7-12) battling cancer about their self and others through drawing. Drawings are believed to reveal a child's inner mind. 78 drawings were reviewed and found what children perceived of themselves. The drawing mainly portrayed weak self-images. Some of their descriptions included:

- A bald boy
  - A laterally inverted portrait
  - A girl without hands
  - A boy wearing a mask
  - A boy with no body parts
  - A boy standing alone with a kite
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- ❖ According to the researcher, all these portrayals either reflected that they do not consider themselves complete, they were trapped in their sick bodies or isolated from the world.
  - ❖ In most drawings children portrayed themselves as bald. It is an obvious sign to themselves and their peers that they are ill. Those drawings which portrayed them without hair was often combined with another picture of a child with hair. Therefore, perceived hair loss as being different from others.
  - ❖ The researcher noted that many children drew themselves with masks. Children believe masks are to hide the changes in their faces from others.
  - ❖ Something else the research noted was most facial expressions of themselves in the drawings mainly reflected grim serious faces and sadness.

This study represented that children are aware of their body image and that their cancer treatment is affecting them in a negative way.

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Another study done was to explore adolescent's (ages 12-18) perspectives of the impact of physical changes caused by cancer treatment. The study was conducted through a interview. The overriding theme that emerged from how the teens perceived their body image was "I don't look normal" "I look ugly" or "I look sick." These thoughts aroused feelings of vulnerability which they stated "people look at me." Hair loss and the presence of central venous catheter were the two major factors responsible for the altered body image. Adolescents stated:

- ❖ "Losing your hair it changed your general look, your face, the whole person, the image you display."
- ❖ "When you don't have hair you look sick."

- ❖ “Look at me, I’m not nice looking at all, I have no hair, I have a big scar, a big thing here, I have dry skin, I have small dry pieces of skin everywhere on the face and on my nose. This does not make a nice looking face.”
- ❖ “I don’t want to go back to school until my hair grows back.”
- ❖ “Look at me. I’m not nice looking at all; there never will be a girl that would want to go out with me.”

As you can see by these adolescents’ thoughts they have a negative body image that is impacting their lives. From this interview we can conclude that many adolescents have a poor body image when going through cancer treatment.

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## **Childhood Cancer Camps**

- ❖ Camp programs for children who have cancer provide support to children and their families that may no longer be accepted or understood by peers.
- ❖ Camp promotes a positive peer interaction and therapeutic activities in a non threatening, medically safe environment to promote cognitive and emotional development.
- ❖ Provides an escape from stressors at home, school or the hospital.
- ❖ Activities include boating, music, photography, kayaking, horseback riding, archery, arts & crafts, rock climbing, swimming, sailing, camp fires, camp outs, attending theme parks and more!
- ❖ Some camps offer social support for acknowledging those children who have passed away and supporting the camper’s grief process. Activities may include a memory garden or a balloon launch to recognize their peers that have passed. Some camps even do a hair cutting ceremony to support other children with cancer.
- ❖ **ALL FREE OF CHARGE!**
- ❖ Different camp programs designed to meet children’s and families needs.
- ❖ Examples: Camp Happy Times, Camp Sunrise, Camp Happy Times, Sister Pats Kids Camp, Camp Simcha, Hole In the Wall Gang, Hospital Outreach Program.

Examples:

### **Sister Pat's Kids Camp**

- ❖ An outreach ministry of St. Helen’s Church in Westfield, NJ that provides a weeklong camping program for children afflicted with cancer and other related blood disorders.
- ❖ Promoting a comprehensive, safe camp experience for children living with cancer or serious blood disorders.
- ❖ Helping children explore their interests and inner selves through sports, the arts and the outdoors, while providing for their health-related needs.
- ❖ Giving each child an opportunity to have a week of fun and take from camp a renewed sense of confidence, compassion and hope.

- ❖ *These children are recommended by the Division of Pediatric Oncology and the Division of Hematology and Blood and Marrow Transplantation at Morgan Stanley Children's Hospital of New York Presbyterian, Columbia University Medical Center.*

### **Camp Sunrise**

- ❖ Sunrise Day Camps bring the simple pleasures of childhood back to children struggling with cancer, changing months of loneliness and isolation into summers filled with sunshine, laughter and happiness. And because Sunrise is a *day camp*, it does all this while allowing the children to continue their medical treatment and enjoy the comfort and safety of their own homes at night.
- ❖ All activities at camp are designed with special features to best accommodate chronically ill children, with medical personnel always available to provide expert care if needed.
- ❖ Activities can include the many that camp offers including arts and crafts, drama, yoga, sports of all sorts, mini golf, playground, low ropes course, climbing wall, and music, and swimming.

## **Why is the Problem Important?**

It is important that we not only treat patients physically but psychosocially as well. Children and adolescents are going through many body changes. Physical symptoms of cancer and the treatments can have a serious social and emotional impact on children and adolescents. Negative body image in children with cancer can lead to academic, social and psychological impairment, low self-esteem, depression, social anxiety and alter compliance of a treatment plan

It is important that nurses identify these psychosocial issues when they arise and intervene early to improve patients self esteem, body image and overall their quality of life.

### **PICO-TS Question**

Among pediatric patients with cancer, does referral to childhood cancer camps compared to no intervention improve overall body image over a 2 month period on a pediatric hematology/oncology unit?

# Research Review

## **Systematic Review Article (Article 1)**

- ❖ Method - Review of the literature from 2001-2013 included 20 articles
- ❖ Studies found that camps help children with cancer and their siblings discover and explore their interests as well as enhance their physical and emotional skills including self-esteem.
- ❖ It has been hypothesized that these changes that the camp promotes help the children and families cope more effectively with the illness.
- ❖ Camp can increase a child's self-competency which can help a child feel good about themselves and thereby feel less anxious.
- ❖ One study found that camp had no outcome of a child self-concept, which may be due to the timing of the study because another studied observed no effect on depressive symptoms or self-competency directly after camp but did observe positive improvements 4-6 months after camp.
- ❖ Another study found no changes in adjustment with post scores compared to normative data.
- ❖ Overall most of the studies found that childhood cancer camps overall improve self esteem of children

## **Mixed-Methods Research Article (Article 2)**

- ❖ Method – Mixed method research design at Camp Little Red Door which is a camp specific to children 8-18 years old with cancer and their siblings. 29 campers were given a pre-test when they arrived at camp and a post test at the end of the camp session. Questions were derived from the Rosenberg self esteem scale. Out of those 29 campers 8 provided a 3 month phone follow up interview about their experience at camp.
- ❖ The pretest and posttest questionnaire showed a uniform positive movement for independence, social skills and self-esteem, with a significant difference found for self-esteem.
- ❖ Oncology camp gave participants a strong feeling of social acceptance and an increase in self-esteem.

These are actual interview responses that identified an increase in self-esteem:

- ❖ “Well everyone is nice, and no one cares that I have cancer and have no hair; lots of kids have no hair. And, like no one asks about my scare. Plus, there are so many fun activities. And I get to make lots of new friends who understand that having cancer doesn't make you weird.”
- ❖ “Im just a regular kid. Most of the time, people don't treat me like that but at camp im just normal.”

- ❖ Campers found value in being around others who understood what it is like to live with cancer.
- ❖ Themes of a supportive community and sense of normalcy
- ❖ Campers with cancer had increased feelings of peer acceptance when comparing themselves to other children at camp versus to their healthy peers outside of camp

### **Qualitative Research Article (Article 3)**

- ❖ This study investigated how childhood cancer camps continued to play in the lives of adults surviving childhood cancer (ASCC) and how they benefitted from camp when they were diagnosed with cancer
- ❖ 23 adults surviving childhood cancer were used. They were recruited from 9 childhood cancer camps across the United States. During the data collection participants were 18 years or older at the time but identified having cancer between the ages 1 and 18. Interview took place asking about their camp experience and what camp meant to them.

These are actual interview responses that identified a sense of normalcy at camp:

- ❖ At the age of 12, Leo was diagnosed with Acute Lymphoblastic Leukemia (ALL). He was treated for 26 months with a combination of chemotherapy, radiation, and surgery. Leo attended camp for 4 years when he was a teenager. He stated “We all had tubes sticking out of our chests. It would be pretty awkward to go to a regular public swimming pool. So, you go there, and you got a hundred kids in the same situation. And so, you are all cancer patients, equally together, but you are going and being able to do something normal.”
- ❖ Nina was diagnosed with malignant schwannoma in her head and neck at age 10. She was treated with 2 surgeries, chemotherapy, and radiation. Nina first went to camp when she was on treatment and had a Broviac catheter. “It was fun. It was awesome. It’s a magical experience that all of a sudden, you were transported to this land of “nothing was wrong with you.” You were a normal kid, and you didn’t have to worry about your Broviac or whatever. And, for 10 days, you could do all the things that regular kids could do, but at the same time, if you’d get sick, everybody understood. You were kept safe.”
- ❖ Childhood cancer camps play an important role in adults surviving childhood cancer (ASCC) survivorship, providing them with ongoing social, emotional and informational support.
- ❖ Camp provided opportunities to identify with other campers, form meaningful friendships and feel less isolated
- ❖ Camp offered a place to feel “normal” and engage in activities that would otherwise be restricted
- ❖ Received informational support that assists them in their daily lives

# **Strengths and Limitations**

## **Strengths**

### Systematic Review

- ❖ Systematic review had large sample sizes and had more rigorous research methods which included one study that had a control group.
- ❖ Data was collected and different points in time which strengthened the understanding of the impact of the camp on outcomes.
- ❖ Camps were reviewed not just in U.S.A and Canada but globally.
- ❖ Review of the research illuminates certain areas that were previously unexplored.
- ❖ Started to analyze outcomes by subgroups including age, gender, nationality and patient/sibling status.
  - One study showed positive, negative and no outcomes on certain subgroups.
- ❖ Can be generalized to other camp programs for other children living with chronic health conditions.
- ❖ Provides more specific ideas and greater clarity for potential future research.

### Other Two Studies

- ❖ Qualitative analysis to gain in-depth perspective of participants.
- ❖ Small studies are able to provide a foundation for exploratory studies and further research of childhood cancer camps.

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## **Limitations**

### Systematic Review

- ❖ Changes in camp don't occur in a linear fashion. Some studies did not include posttest scores at 2 or 3 time points.
  - Ex. Children may be upset that they have to leave their friends from camp and may provide a poor score on a camp posttest.
- ❖ Limited body of research to review.

### Other Two Studies

- ❖ One study lost paired identity, therefore not being able to compare pretest and posttest scores individually.
  - ❖ Small sample sizes and the similarity of participants limit the ability to generalize the results.
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## Study Quality

Critical Appraisal Skills Programme (CASP) was used to appraise study quality.

One Systematic Review Study

- ❖ Aims of research were clearly stated.
- ❖ Appropriate study design.
- ❖ Relevant studies were included from appropriate databases.
- ❖ Results are clearly described and any variation in results was discussed.
- ❖ The results can be applied to my research project.
- ❖ The research is valuable and findings can be used in future research.

Two Qualitative Studies

- ❖ Aims of research were clearly stated.
- ❖ The qualitative methodology is appropriate for addressing the goal.
- ❖ Research design is appropriate to the aims of the research.
- ❖ How the participants were collected was appropriated.
- ❖ How the data was collected was clear and justified the research aim.
- ❖ Ethical standards were maintained.
- ❖ The analysis provided in depth descriptions and themes were derived from the data.
- ❖ Findings are discussed and clearly stated.
- ❖ The research is valuable and can be used in future research.

## Table of Evidence

Research Article/Author/Year	Study Design	Sample	Outcome Measure	Results	Level of Evidence
<p><b>Camp Programs for Children With Cancer and Their Families: Review of Research Progress Over the Past Decade</b></p> <p>Alexandra Martiniuk, Mariana Silva, Michael Amylon, Ronald Barr 2014</p>	Systematic Review	20 Articles	Overall to measure camps providing medically safe place for campers, providing a normalizing camp experience, and aiming to improve psychosocial functioning.	<p><b><u>Childrens Psychosocial Needs:</u></b></p> <p>-Studies found that camps help children with cancer and their siblings discover and explore their interests as well as enhance their physical and emotional skills including self-esteem.</p> <p>-It has been hypothesized</p>	Level 1

				<p>that these changes that the camp promotes help the children and families cope more effectively with the illness. For example, children who have obtained self confidence from this camp can face peers at school who may question their physical appearance or providing increased time and opportunity to make new friends and have fun.</p> <ul style="list-style-type: none"><li>-Camp can increase a child's self-competency which can help a child feel good about themselves and thereby feel less anxious.</li><li>- Two studies found that camp improved children's comprehensive evaluation scores called health quality of life.</li><li>-One study found that camp had no outcome of a child self-concept, which may be due to the timing of the study because another studied observed no effect on depressive symptoms or self-competency directly after camp but did observe positive improvements 4-6 months after camp.</li><li>-Another study found no changes in adjustment with post scores compared to normative data.</li></ul> <p><b><u>Family:</u></b></p> <ul style="list-style-type: none"><li>-Two studies found that camp can be positive experience for parents, one of which found that camp improved a mother's psychosocial well being.</li><li>-Another study that</li></ul>	
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				contained a control group found that parent attendees reported significantly better family function, social support, parent skills and coping than non attendee parents.	
<p><b>Camp War Buddies: Exploring the Therapeutic Benefits of Social Comparison in a Pediatric Oncology Camp</b></p> <p>Shay Dawson, Doug Knapp, James Farmer 2012</p>	Mixed- Method Research Design	<p>Quantitative – 29 Campers</p> <p>Qualitative – 8 Campers</p> <p>(Ages ranged from 8-18 years old)</p>	To measure the effect of attendance at a pediatric oncology camp designed to support the psychosocial needs of youth 8-18 years of age.	<p><b><u>Quantitative Findings:</u></b> -The pretest and posttest questionnaire showed a uniform positive movement for independence, social skills and self-esteem, with a significant difference found for self-esteem. -Oncology camp gave participants a strong feeling of social acceptance and an increase in self-esteem.</p> <p><b><u>Qualitative Findings:</u></b> -A presence of the camp war buddy philosophy in those campers found value in being around others who understood what it is like to live with cancer. -Themes of a supportive community and sense of normalcy -Campers with cancer had increased feelings of peer acceptance when comparing themselves to others who are similar in the camp versus comparing themselves to their peers outside the camp</p>	Level 6

<p><b>Childhood Cancer Camps: Their Role in Adults Surviving Childhood Cancer Lives</b></p> <p>Asher E. Beckwitt 2014</p>	<p>Qualitative Research</p>	<p>23 Adults Surviving Childhood Cancer (ASCC). Recruited from 9 childhood cancer camps across the U.S. They were 18 years or older at the time of data collection but identified having cancer between the ages 1-18. Majority of the participants (n=11) were diagnosed with ALL.</p>	<p>To understand the roles childhood cancer camps play in enhancing Adults Surviving Childhood Cancer (ASCC) psychosocial and emotional well-being and access to information.</p>	<p><b><u>Qualitative Findings:</u></b>          -Childhood cancer camps play an important role in adults surviving childhood cancer (ASCC) survivorship, providing them with ongoing social, emotional and informational support.          -Provided opportunities to identify with other campers, form meaningful friendships and feel less isolated          -Camp offered a place to feel “normal” and engage in activities that would otherwise be restricted          -Received informational support that assists them in their daily lives</p>	<p>Level 6</p>
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## **Recommendations**

### **Key Findings**

- ❖ As evidence by three studies, overall childhood cancer camps increase self esteem and develop a positive body image for children with cancer.

### **Further Research**

- ❖ A larger scale and more specific study is needed to answer many outstanding questions  
Ex. Certain interventions inside the camp that cause a positive change, neutropenic children and activity restrictions etc.
- ❖ Further research includes a more diverse sample and subgroups.

- ❖ Research should continue for ongoing social, emotional and informational support for adults surviving childhood cancer.
- ❖ Overall, further research is needed.

### **Current NYP Initiatives and Policies**

- ❖ Nurses in the pediatric hematology and oncology clinic observe who would benefit the most from cancer camps and then they refer the families and patients to these camps. Useful information is provided through brochures and applications.
- ❖ Some nurses also volunteer their time at camps.
- ❖ Hospital Outreach Program – While children are inpatient and too sick to attend camp, the camp comes to them and provides arts & crafts, games, and activities for children to deliver fun and friendship!

### **Next Steps**

- ❖ As I saw on the clinic the nurses play a big role in referring children to these services and they are doing an amazing job at it!
- ❖ While in inpatient, the hospital outreach program comes to the children and provides them opportunities to play and learn.
- ❖ Morgan Stanley Children's Hospital is currently playing an active role in providing services and information of camps to children and their families affected by cancer.

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