



Cancer Survivor Camps: Programming for Young Adult Cancer Survivors

by

Emily Saunders

A Master's Project
Presented to the Arts and Administration Program
of the University of Oregon
in partial fulfillment of the requirements
for the degree of
Master of Science in Arts and Administration

June 2012

**Cancer Survivor Camps:
Programming for Young Adult Cancer Survivors**

Approved: _____

Dr. Patricia Dewey
Arts and Administration Program
University of Oregon

Date: _____

Abstract

This research project is a study of cancer survivor camps and their programs for young adult cancer survivors. The study analyzes the benefits of these camps and the programs' effectiveness in improving the quality of life for camp participants. The literature review emphasizes that social support for young adult cancer survivors is very important, specifically for psychosocial rehabilitation. The social support young adult cancer survivors find at camp through the use of camp programs can be extremely beneficial. The research addresses the gap in the literature as to what programs are effective and engaging for young adult cancer survivors. This research consists of document analysis of peer-reviewed articles which survey young adult cancer survivors to determine their resource needs, reflective journals about camp participants engagement in programs collected in my role as a program facilitator, interviews of camp administrators as key experts in the field and an online survey of young adult cancer survivors about camp programming and its effectiveness.

Keywords

Cancer camps, young adult cancer, oncology camps, young adult cancer resources, psychosocial support oncology, support young cancer survivors, art program oncology.

Acknowledgements

First, I want to thank my fellow young adult cancer survivor friends for their peer support and understanding. You are the ones I turn to for perspective, because you know what it was like to live through cancer as a young adult.

I want to thank my research advisor Dr. Patricia Dewey for her continued guidance and encouragement throughout this project. Thank you Patricia.

I would also like to recognize the two cancer survivor camp's directors who so graciously donated their time to help with this research. Thank you Beth Jones and Tonia Farman for the incredible work you do at these camps.

I dedicate this research to my young adult cancer survivor friends who have had their lives cut short by cancer.

Curriculum Vitae

Education:

Masters in Arts and Administration & Masters Certificate in Nonprofit Management

University of Oregon 2010-2012 GPA 3.89

- Arts in Healthcare Concentration
- Practicum at Sacred Heart Medical Center at Riverbend for one year
- Understanding the nonprofit structure, strategic planning, management & fundraising practices
- Developing graphic design logos, letterhead and advertising for nonprofits

Bachelor of Arts in Art History & Minor in Architecture

Portland State University 2002-2006 GPA 3.47

- Degree encompassed a detailed art historical understanding of all art periods
- Obtained a studio emphasis in photography

Associates Degree in Interior Design

Portland Community College 2002-2006 GPA 3.84

- Helping clients with specific design needs, color selections and spatial planning
- Choosing the products, materials, finishes and lighting designs for the space
- Record keeping, building presentation boards and presenting designs

Experience:

Art Program Specialist & Resource Specialist at Camp Mak-A-Dream

Cancer Camp for Kids, Teens & Young Adults in Montana – Camp Season for 2011 & 2012

- Developed photojournal & movie-making workshops
- Facilitated photojournal & movie-making workshops
- Collaborated with the Program Staff about camp's program activities
- Presented resources for each cancer survivor age group/camp session
- Posted Facebook updates throughout the summer highlighting camp's activities

Art in Healthcare Intern at Sacred Heart Medical Center at Riverbend

Eugene, Oregon – 2011-2012

- Assisted the Coordinator of The Center of Mission for Sacred Heart
- Assisted with conference and symposium event planning
- Developed the Docent Program for art tours of Riverbend's artwork
- Installed artwork for Riverbend's art gallery and for permanent displays

Developed Young Adult Cancer Survivor Support Group

Eugene & University of Oregon Community with support from Disability Services – 2012-2012

- Utilized my knowledge as a core member of the Young Adult Cancer Support Group in Portland
- Met with Disability Services at UO to develop Eugene's Young Adult Cancer Survivor Support Group
- Designed and distributed flyers about the group around the community
- Attended group meetings every 2 weeks for 2 years as a member of the group

Marketing and Social Media Chair for the Association of Fundraising Professionals

University of Oregon Collegiate Chapter of AFP

- Developed the AFP Facebook Page & OrgSync Group Page
- Posted Fundraising Event Announcements on the site
- Organized and categorized the association's information files

Recognition:

Excellence in Diversity Scholarship (2011-2012), *University of Oregon*

Cancer for College Scholarship (2011)

The SAMFund Grant for Surviving and Moving Forward as a Young Adult Survivor (2010)

Table of Contents

Chapter I:	Introduction	1
	Problem Statement	2
	Conceptual Framework	3
Chapter II:	Research Methodology	7
	Researcher Role	9
	Methodological Paradigm	9
	Research Design	10
	Data Collection & Analysis Procedures	12
	Recruitment & Consent	14
	Conclusion	15
Chapter III:	Literature Review	16
	Section I: Art in Healthcare	17
	Art in Healthcare – An Overview	17
	Benefits of Art Programs in Healthcare Settings	21
	Art Programming & Cancer Patients	22
	Outcomes of Art Programming for Cancer Patients	25
	Section II: Young Adult Cancer Survivors (YACS)	28
	Young Adult Cancer Survivors Needs	28
	Psychological & Psychosocial Issues of YACS	33
	Quality of Life Issues	37
	Benefits of Peer Support	39
	Section III: Cancer Camps	42
	Overview of Cancer Camps	42
	Effects of Camp on Young Survivors	43
	Camp Programming	44
	Program Evaluation	47
Chapter IV:	Data Collection, Analysis & Findings	50
	Data Collection	51
	Data Analysis	51
	Findings	51
Chapter V:	Summary & Discussion	58
	Summary	59
	Discussion	60
	Implications	62
	Recommendations	64

Appendices	66
A: Conceptual Framework Schematic	67
B: Research Timeline	68
C: Research Instruments	69
D: Research Clearance for Master’s Project	70
E: Recruitment Letter for Interviews	71
F: Consent Form for Interviews	72
G: Interview Questions	74
H: List of Participants Interviewed	75
I: Recruitment Letter & Consent Form for Survey Posting	76
J: Survey Questions	77
K: Survey Results	79
L: Chart of YACS Camp Program Participation	81
List of Figures	
Figure 1: National Survey of Arts Programs in U.S. Hospitals	19
Figure 2: Percentage of Total Cancer Population by Age Group	29
Figure 3: Aspects of Cancer Treatment that cause Psychological Trauma	34
Figure 4: Visual Model of the Environment that Drives Programs	49
Figure 5: Reason’s Why Young Adult Cancer Survivors Attend Camp	52
Figure 6: Why YACS Found a Specific Program to be the Most Engaging	52
Figure 7: Topics that YACS Appreciated Being Able to Discuss	55
Figure 8: Topics YACS Would Appreciate Discussing in the Future	56
References	82

Chapter I: Introduction

This research is a study of cancer survivor camps for young adults to analyze the benefits of camp on participants' quality of life. The term cancer 'survivor' within this context is used to describe an individual from diagnosis through the rest of their life. The term 'young adult' cancer survivor refers to any person between the ages of 18 and 40 when diagnosed with cancer. The research analyses the benefits of these camps through document analysis of peer-reviewed articles which survey young adult survivors to determine their resource needs, observation of young adults participating in camp programs, interviews of camp administrators and a survey of young adult cancer survivors about camp programming. The research addresses the gap in literature which remains to explore what programs are effective and engaging for young adult cancer survivors within a camp setting.

Problem Statement

There are many stressors for young adult cancer survivors adjusting to such a nonnormative life event. Nonnormative life events are unusual occurrences that are not normally anticipated and may have a major impact on development. The occurrence, pattern, and sequence of these events are not applicable to many individuals; "experiencing a chronic disease in early adulthood is a nonnormative event" (Fisher, 2005, p. 658).

Diagnosis and treatment of cancer affects a cancer patient in many life changing ways. There are many physical and emotional impacts of cancer and its treatment. Cancer-related fatigue, which interferes with usual functioning, is the most prevalent symptom for cancer patients; 75% of patients with various solid cancerous tumors had significantly increased fatigue scores compared to a matched control population (Bar-Sela, 2007). During chemotherapy treatment, fatigue symptoms can reach 100% of patients (Bar-Sela, 2007).

Along with fatigue, emotional distress also occurs from treatment; 25% of cancer patients meet diagnostic criteria for major depression or anxiety disorders (Bar-Sela, 2007). These disorders cannot be considered ‘normal’ reaction and they have a severely detrimental effect of the patient’s quality of life (Bar-Sela, 2007). Even after treatment the cancer survivor often describes two sides of survival – “one of celebration and hope, and one of uncertainty and fear” (Yi, 2010, p. 1). Post-treatment often includes late medical and psychosocial effects as well, such as post-traumatic stress symptoms, complications and disabilities (Yi, 2010). Stressors for cancer survivors include the diagnosis, prognosis, treatment, multiple hospitalizations, adapting to treatment, lengthy treatment, significant side effects, follow-up assessment for late effects and fears of recurrence.

Social support has been shown to decrease stress, to calm and reassure survivors, and to help teach them long-term coping strategies. Through document analysis of cancer survivor camp studies, it is significant to note that these camps are effective in decreasing stress and enhancing coping strategies (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2005). However, all of the studies acknowledge a lack of knowledge regarding efficacy of camp programs, specifically in regard to descriptive assessments designed to better understand the engagement and perspective of participants.

Conceptual Framework

Research was gathered from a variety of studies on what makes an effective program for cancer patients outside of a camp setting, to better identify indicators of effectiveness in programming for cancer patients overall. Focus was then narrowed to art programs for cancer patients outside of a camp setting to identify indicators of effectiveness in this form of programming. Indicators for effectiveness were assessed through standardized tests for

depressive affects, anxiety, social engagement and the measure of pleasure and participation in activities by cancer patients. These studies measured effectiveness through the use of: in-depth interviews, questionnaires of the patient before and after the art program, surveys addressing if they liked the program and suggestions for improvements of the program (Bar-Sela, 2007; Nainis, 2006; Singer, 2010; Walsh, 2007; Wood, 2010; Yi, 2010).

The in-depth interviews included questions about the patients' expectations, experiences with creative activities and types of psychological conflicts (Singer, 2010). The questionnaires included a selection of the following to determine the mental well-being of the participants before and after the art program: Hospital Anxiety and Depression Scales (HADS), Trier Coping Scales, Brief Fatigue Inventory (BFI), Edmonton Symptom Assessment Scale (ESAS), Beck Anxiety Inventory (BAI) or Spielberger State-Trait Anxiety Index (STAI-S) (Bar-Sela, 2007; Nainis, 2006; Singer, 2010; Walsh, 2007). These questionnaires established a base-line and a comparison to that base-line following the art program. At the end of the art program, or sometimes after each session, the patients were asked for input as to how the program could be improved, if they liked the session, and if they felt comfortable making the art (Nainis, 2006; Singer, 2010).

The outcomes from these studies were significant, especially considering the relatively inexpensive interventions that entail an art therapist or artist's time and the cost of art supplies. Along with patients' willingness to creatively express themselves, a marked improvement in mental well-being was measured. First, anxiety in patients was reduced significantly. Second, depression in patients was significantly lowered. These studies, detailed in the literature review, prove that the arts can be used for therapeutic interventions, as a way of transformation and

healing. “It has been shown that patients who feel better about themselves and are more hopeful, live longer with cancer” (Lane, 2006, p. 74).

After a comprehensive literature review of art programs and their effectiveness for cancer patients, research was conducted on the program needs of young adult cancer survivors. Young adult survivors are persons between the age of 18 and 39 years of age when diagnosed with cancer. The increase of long-term survival has made quality of life issues more prominent for young adult cancer survivors. “In the past two decades more children (and young adults) have survived chronic illnesses (longer) and the role of camps has evolved. Social support in health and chronic illness has been one of the most frequently researched concepts in the past decade, both as a coping resource and as a protective factor related to stress and coping” (Decker, 2007, p. 2).

Research was gathered through peer-reviewed articles that surveyed young adult cancer survivors to determine what types of social support care needs and preferences were needed or desired by this community. These surveys uncovered a need for programs that address issues of survivorship, education and building bridges of support. While there is no single unified definition of social support, for the purposes of this research social support refers to interpersonal relationships assumed to protect people from the damaging effects of stress.

In one peer-reviewed article a survey of 217 young adult cancer survivors was captured. The findings were that upward of 98% of respondents expressed a desire or need for age-appropriate cancer information. Three fourths of respondents indicated a need or desire for peer support programs. Seventy-eight percent wanted information about camp programs or retreats. And sixty-two percent of respondents wanted programs in the form of camps, retreats, or

workshops that offered cancer education and support appropriate for young adult survivors (Zebrack, 2009, p. 352).

In this review of the literature, it was found that more programs are desired on topics that deal with grief and loss, intimacy and dating, late effects (especially fertility), mental health counseling, obtaining and maintaining health insurance coverage and self-improvement in the form of nutrition and exercise (Zebrack, 2009, p.780). “The main intent of these programs is to instill skills and encourage survivors to apply at home what they learned at camp...” (Zebrack, 2009, p. 781)

Lastly, an extensive review of literature focused on cancer camps for children. These studies indicate that cancer camps are effective in decreasing stress and enhancing coping strategies (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2005).

The next chapter will detail the research methodology undertaken, including the researchers role, research design, data collection and analysis procedures.

Chapter II: Research Methodology

Research Methodology

The purpose of this study is to address the gap in the literature in regard to what cancer camp programs are effective and engaging for young adult cancer survivors. This research consists of document analysis of peer-reviewed articles which survey young adult cancer survivors to determine their resource needs, reflective journals about camp participants engagement in programs collected in my role as a program facilitator, interviews of camp administrators as key experts in the field and an online survey of young adult cancer survivors about camp programming and its effectiveness.

Overall, there is a lack of knowledge about these camp programs, specifically in regard to descriptive assessments that gain the perspective of young adult cancer survivor camp participants. The benefit and effectiveness of these programs was gathered through an online survey of young adult cancer camp participants to gain their descriptive assessment of camp programs.

The main research question is: What are the benefits of cancer survivor camps for young adults? The sub-questions are: What programs are effective? What art programming is effective? How do these camps aim to improve the quality of life for young adult camp participants? A program's effectiveness in this context refers to the programs ability to increase social support, decreasing anxiety, lower depression, decrease stress and enhance coping strategies.

Informed consent for the online survey was gained through an introductory statement at the beginning of the survey. This introduction served as a consent form. The statement informed the participants that completing the survey constituted their consent. The introduction included a brief statement about my observations as a program facilitator last summer. I stated that my observations in my role as a program facilitator will be incorporated into the research.

Also, informed consent for the interviews of camp administrators was provided in the form of an informational letter that was signed by the camp administrator before the interview took place.

Researcher Role

The purpose of this research grew out of an interest in resources and support for young cancer survivors within the nonprofit sector. This emergent research of resources and social support for young survivors led to a focus on cancer survivor camps for young adult cancer survivors. As a young adult cancer survivor, I was motivated to study what social support and programming exists for young adult survivors and what benefits there are to these social support structures.

I come to this study with subjectivity and transparency, as I am emotionally engaged with the subject matter as a young adult survivor. As a survivor I attended one of these cancer camps, after which I went on to receive a master's level education in art programming for the nonprofit sector. I returned as a camp staff member in art programming for one of these cancer camps in 2011. As a camp program staff member for the 2011 camp season I gained inside access and perspective on these programs for young survivors. As a facilitator of camp programming I documented my observations in reflective journals. This educational, professional, and personal background all led to a committed life-long interest in the topic of this study.

Methodological Paradigm

The research relied on interpretive theory to describe how the campers understood and found meaning in their lives through these programs, and is a logical companion to observation and staff interviews (Newman, 2003). The applied methodology of this research is post-positivist, as it is subjective. This paradigm influences the research design through descriptive data collection through observation of camp program participants.

These camps are some of the only places where young adult survivors can come together and find the social support provided by other young adult survivors their own age, while outside the walls of a medical infrastructure. This research project contributes to the field of study through observation of participants and their engagement in camp programming. The observation of participants within camp programs explores first-hand the effectiveness of the programs. It is important to note that all programs are attended voluntarily by campers, and no program within this camp has required attendance. I have had high levels of access to this group and lived within their reality, at camp, every day for seven days. More information is also required in regard to young adult cancer survivors' resource needs; this age demographic of survivors has far fewer resources in print than its younger counterpart.

The studies, assessments and surveys in my literature review have both marked a need for more programs for young adult survivors and have shown the positive affects on children's psychosocial well-being from participating in camp (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2005). Decreasing stress and enhancing coping strategies in young adult survivors during the adjustment of such a non-normative life change is crucial. The stressors are overwhelming for young survivors and these camps and their social support and programming have shown conclusively to help these young survivors in a myriad of ways.

Research Design

The strategy of inquiry utilized document analysis of previous studies conducted of this population, immersive prolonged engagement and observation of campers participating in programming at the case-study site, informational interviews of camp staff members, and a survey of young adult camp participants, this strategy sought to answer the questions: What are

the benefits of cancer survivor camps for young adults? What programs/art programs are effective? How do these camps improve the quality of life for young adult camp participants?

A programs' effectiveness in this context refers to the programs ability to increase social support, decreasing anxiety, lower depression, decrease stress and enhance coping strategies. This research design follows a similar strategy of inquiry as previous studies of programs for cancer survivors, which measured programs effectiveness. To analyze the effectiveness of these programs the researchers used: literature review, in-depth interviews, and surveys of cancer survivors addressing if they liked the program and suggestions for improvements of the program (Bar-Sela, 2007; Nainis, 2006; Singer, 2010; Walsh, 2007; Wood, 2010; Yi, 2010).

Qualitative methods of data analysis were used in collecting journal entries reflecting covert observation of the young adult campers participating in camp programs, developing graphs of program efficacy (delineated by engagement and participation), and summarizing informal, candid interviews of administrators of the camp. This conceptual framework will result in the triangulation of repeatable findings. No confidential information was collected at the case study site in my role as a facilitator of art programming at a cancer camp. I observed young adult participants at camp and graphed their engagement in programs while at camp. No names were collected while graphing their engagement in camp programs.

As for ethical concerns, young adult campers remain anonymous and observation in my role as a program facilitator was done covertly. This population is a vulnerable population with high research risk. This is one of the main reasons I conducted most of my research with the use of document analysis of previous studies, covert observation and informational interviews with camp administration. Data from a survey of this population was collected through the use of an

online survey provider, and all human subjects remained anonymous. Participants in the survey were recruited through a posting on two Facebook pages of cancer survivor camps.

There is a reduced risk by using peer-reviewed documents that have already formed sound research design of participants for diagnostic purposes. There is also reduced risk to this vulnerable population by covertly observing young adult campers, as opposed to directly interviewing and surveying them.

Data Collection and Analysis Procedures

Data collection methods includes reflective journals that recorded observations of program participation and charts of program engagement (collected in my role as a program facilitator in the summer of 2011); an online survey of camp program participants; informal interviews of the staff; and document analysis of studies previously conducted of this population.

The qualitative methods of data analysis in this research include data that I collected in my work as a program facilitator for a nonprofit cancer camp in the summer of 2011. As a part of my work as a program facilitator I observed campers participating in programming and charted program efficacy (delineated by the number of campers engaged in each program). I also reflectively journaled about campers' participation in my role as a program facilitator at the camp. This data was collected for non-research purposes, as a part of my role as a program facilitator. I am now using this data, which I collected as a program facilitator, for this research.

The site selected for my case study is a national nonprofit cancer survivor camp for children and young adults called Camp Mak-A-Dream in Montana. I selected this site as it is a mid-size cancer survivor camp with a variety of programs that are typically offered within a cancer camp. After my first year in a master's level education in art programming for the nonprofit sector, I returned as a camp staff member in art programming for this cancer camp in

2011. As a camp staffer for the 2011 camp season I gained inside access and perspective on these programs for young survivors.

As a facilitator of camp programming I documented my observations in reflective journals. For this research observations recorded in reflective journal entries will focus entirely on young adult camp program participants whom I observed from June 15th to June 22nd, 2011. This is representative of the Young Adult Camp Session for the 2011 camp season.

There are six camp sessions over the summer, approximately one-week long each, of varying ages within this population. This research only captures data through observation of the young adult camp session, and all of the campers identities will remain anonymous. Data collection methods will include reflective journaling on observations of program participation, an online survey of young adult cancer survivor camp participants, charts of camp program engagement, and informal interviews of the staff and document analysis of surveys and studies previously conducted of this population.

Research methodologies allow my observations as a program facilitator to be used for this research, because the reflective journal entries were collected in my role as program facilitator not as a researcher. For this research observations recorded in reflective journal entries (of which participants remain anonymous) will focus entirely on young adult camp program participants whom I observed as a facilitator from June 15th to June 22nd, 2011.

In addition to the data previously collected as a program facilitator at a cancer survivor camp, I have collected data through summarized informal, candid interviews with administrators of the camp. Along with the document analysis and journaled observations as a program facilitator at the case-study site, the informational interviews of camp staff members, who are key informants within the camp, will inform this research strategy.

Along with the interviews of camp administrators, an online survey of young adult cancer survivor camp participants was used to collect data to build this research. This survey was used to gain the camp participants perspective and assessment of programming at cancer camps. So that all human subjects who participated in the survey remained anonymous the online survey provider Survey Monkey was used.

Recruitment and Consent

Informed consent for the interviews of camp administrators was provided in the form of an informational letter that was signed by the camp administrator before the informal, candid interview took place.

The young adult cancer survivor camp participants were recruited for the online interview through the use of the Camp Mak-A-Dream's Facebook page and the Athletes for Cancer Ambassador's Facebook group page. A link on the two camp's Facebook pages connected the young adult camp participants to the voluntary online survey which requested information about their perspective as participants in these camp programs. This data further addresses the gap in the literature regarding descriptive assessments of camp programs from the perspective of young adult cancer survivor participants.

Informed consent for the online survey was gained through an introductory statement at the beginning of the survey. This introduction served as a consent form. The statement informed the participants that completing the survey constituted their consent. The introduction included a brief statement about my observations as a program facilitator last summer. I stated that my observations in my role as a program facilitator will be incorporated into the research.

Conclusion

Improving the quality of life for these young survivors through effective camp programming is important. The studies, assessments and surveys in my literature review have both marked a need for more programs for young adult survivors and shown the positive effects on children's psychosocial well-being from participating in camp (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2005).

Decreasing stress and enhancing coping strategies for young adult survivors during the adjustment of such a non-normative life event is important. The stressors are overwhelming for young survivors and these camps and their social support and programming have shown conclusively to help these young survivors in a myriad of ways.

The following chapter is an extensive literature review divided into three sections. The first is an overview of arts in healthcare which focuses on art programming for cancer patients of all ages. The second section is an analysis of young adult cancer survivors; their needs, psychosocial issues, quality of life issues and the benefits of peer support for psychosocial rehabilitation. The third section is dedicated to studying cancer camps, their history, programming and the effect of camps on young cancer survivors.

Chapter IV analyzes the findings from the data collected from the observations made of program participation at camp, findings from the online survey of young adult camp participants and interviews with camp administrators. Lastly, Chapter V concludes with a summary and discussion of the implications that resulted from this study and recommendations for future development of programs for young adult cancer survivors.

Chapter III: Literature Review

Section I: Art in Healthcare

Art in Healthcare - An Overview

Little as we know about the way in which we are affected by form, by colour and light, we do know this, that they have an actual physical effect. Variety of form and brilliancy of colour in the objects presented to patients, are means of recovery.

-Florence Nightingale, 1859. (Hume, 2010, p. 20)

This chapter is an in-depth analysis of arts programming in the healthcare field, specifically in relation to cancer patients. Arts in Healthcare is an up and coming field that has spurred significant research. First, an historical overview of the field is described, followed by the benefits of these art programs for patients in general. Secondly, how these art programs that better the quality of life for cancer patients in particular is investigated. This investigation focuses on of how these programs work, what the benefits are, and how research captures that evidence.

Today, more than half of all hospitals in the U.S. have arts programming (Anagnos, 2004). Patient care is the primary focus of these programs; in fact, 96% of hospitals cite patient care as their motivation for having such programs (Anagnos, 2004). Arts in Healthcare did not begin until the 1960's when art was hung on the walls of hospitals to transform the sterile atmosphere into a more caring and comfortable place for patients (Lane, 2006). Although Arts in Healthcare differs from Art Therapy, it too was not acknowledged as a profession until 1960 (Heiney, 1999). In the 1970's large medical centers began installing major art exhibitions to help humanize healthcare settings and emphasize hospitals as a place where beauty and healing connected (Lane, 2006).

One of the first art programs for inpatients came about in the mid 1980's. "We Can Weekend" was one of the first art programs that helped families coping with a cancer diagnosis

and treatment. Art Therapy was a part of the program and included drawings of the family and of current moods (Singer, 2010).

A pioneer report by Roger Ulrich in 1984 directly influenced the way healthcare institutions looked at their patients and healing practices. His study was of the benefits of a room with a view of trees in full foliage for a group of post-surgical patients. Half of the 46 patients recovered with a tree in view, half recovered with a brick wall in view. The “patients with a view of the tree recovered more quickly, used less pain medicine, and suffered fewer complications from surgery” (Ridenour, 1998, p. 399). This does not mean that all patients need views of trees, but that an understanding was formulated that, as Larry Dossey, MD writes, “the most ordinary perceptions have a way of entering the body and influencing rates of healing and degrees of pain” (Ridenour, 1998, p. 399).

Primarily art programming within hospitals for ambulatory patients and outpatients started in the 1990’s. Some examples of these are “Arts in Medicine” started in 1991, “Art that Heals” in 1993 and “Healing Icons” in 1999 (Lane, 2006; Singer, 2010). These first programs were created by nurses and studio artists working together to develop programs to help patients better cope, and emotionally heal through the use of creativity. They found simple art materials were the most effective and least intimidating to patients (Lane, 2006).

“Healing Icons” was the first art program that attempted to evaluate their program in a standardized manner. Six participants in the program gave written feedback using Likert-scaled items and open ended feedback, and although it was positive feedback, it was sparse (Singer, 2010). The major benefits of the program sited from the evaluation included decreasing isolation, expressing feelings, gaining new perspectives, and improving current and future coping (Heiney, 1999).

In the last decade art programming within healthcare institutions has grown significantly. Creative arts programs in which patients and family members participate actively in hands-on art experiences in a healthcare setting is a growing trend (Walsh, 2007).

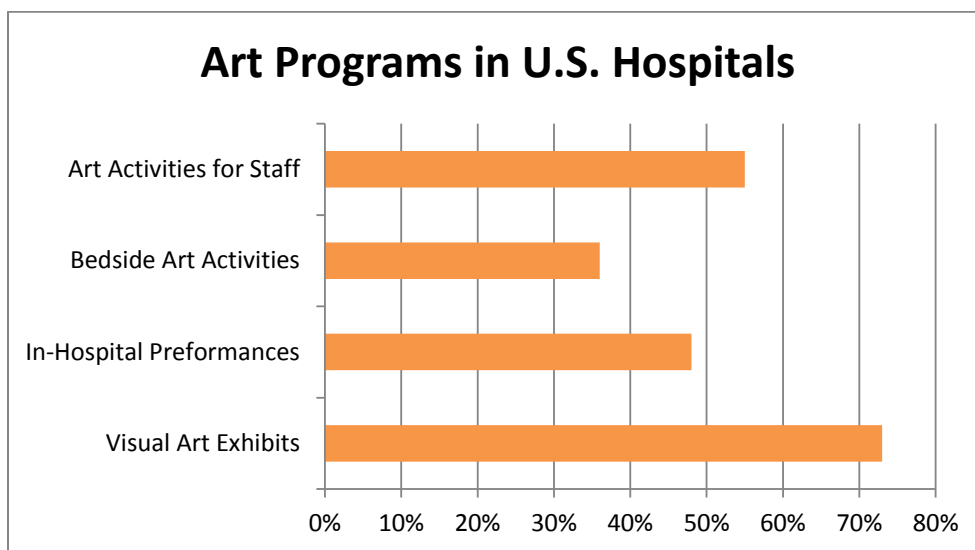


Figure 1: A national survey about arts programs in hospitals with 2,000 hospitals. Source: Americans for the Arts, 2004.

A national survey conducted in 2004 entitled *Cultures of Care: A Study of Arts Programs in U.S. Hospitals* received response from 77% of U.S. hospitals responded. In the survey 73% of hospitals responded that they present the arts because it aids in a patient's mental and emotional recovery; and 79% use arts to create a healing environment (Anagnos, 2004, p. 1). The survey found that more than half of the nation's hospitals provide arts programming for patients, families and staff, of which 73% have visual art exhibitions and 79% have art programs administered by professional staff.

In the beginning, art programs were brought about by collaboration between the healthcare facility and an artist-in-residence. The artist would be invited to work with patients at their bedsides, or "if they were too sick to paint, they could see themselves being painted, or they could tell the artist what to draw" (Lane, 2006, p. 74). In the 1990's health institution-based arts committees were composed of doctors, nurses, administrators, patients, community members and

local artists, all working together to develop strategic plans for arts programming or make selections for installations (Ridenour, 1998).

The use of arts in healthcare settings are used to promote stewardship of place and create interaction in the public spaces of the hospital setting (Borup, 2006, p. 66). The use of evidence-based art installations which display calm, soothing images of nature dramatically change the landscape within a hospital (Hathorn, 2008, p. 9). The use of art in a place that was once a cold and sterile environment expands the visibility of public art and “improves the quality of local life by adding visibility to the communities concerns” within that space (Borup, 2006, p. 66). More than half of all hospitals have art programming today, and the numbers of programs are on the rise. From 2004 to 2007 alone there was an increase from 43 to 49% of healthcare institutions reporting art programs (Sonke, 2009, p. 114).

As art programming and installation became more significant and embedded in the work of hospitals, a call for salaried arts-in-healthcare personnel arose. “Salaries dedicated for arts-in-healthcare personnel are needed to ensure leadership and provide direction for ongoing volunteer training. The integration of arts programs into healthcare facilities requires a philosophical and monetary commitment from healthcare administrators” (Walsh, 2007, p. E15).

It is also important to note that hospital art programs are largely funded by the hospitals themselves; 66% of art programs get their funding from the hospitals general operating fund. (*Cultures of Care Survey*, 2004) In addition to the call for more professionals in the arts-in-healthcare field, the recession took hold and the number of new healthcare buildings decreased in response to budget cuts. In so doing the “role of arts managers in bringing respite and stimulation to existing spaces became more important” (Hume, 2010, p. 19).

Benefits of Art Programming in Healthcare Settings

Even in the most sophisticated hospitals of this nation, patients suffer from afflictions that cannot be relieved by technology or pharmacology. For those patients, compassion and creativity in any form should be called into play.

– Patch Adams, MD (Adams, 1998, p. 401)

In the past decade, at the same time that arts programming was on the rise in healthcare institutions, an increased number of investigators began searching for evidence to determine whether these art education and art therapy programs were beneficial for patients¹ (Singer, 2010). The results from these studies on how the arts have helped the general patient population are that they were “more hopeful, happier, felt better and had less pain. This is true even if the patients do not engage in creative activities themselves but just watch the artists” (Lane, 2006, p. 74).

Bringing artists into the recovery facility provides experiences that counter stress and humanize the environment. “Interactions between patient and artists provide positive distractions and lend social support in environments that otherwise may be isolating and frightening” (Ridenour, 1998, p. 399).

The Americans for the Arts supports Arts in Healthcare and urged Congress for more federal support of these programs stating:

Research confirms that the arts enhance coping thereby reducing patients’ need for hospital care, pain medication, and associated costs. In addition, the arts reduce patients’ level of depression, and situational anxiety, contribute to patient satisfaction, and improve the medical provider’s recruitment and retention rates. (Americans for the Arts: Arts and Healthcare, 2009)

Today art programs are on the rise in healthcare settings due to the efforts of early pioneers in this field and research that supported its use. As of 2004 more than 50% of the nations hospitals

¹ A comprehensive review of these studies can be found by Geue et al. (2010).

provided arts programming for patients, families and staff. 73% of these hospitals provide these programs because they aid in the patients healing and recovery (Americans for the Arts, 2004.)

Art Programming and Cancer Patients

The act of being creative helps patients process and express, within a constructive manner, emotions we would often rather avoid like guilt, shame, sadness, and anger. That's the power of the creative process. It doesn't matter what something looks like in the end, it's what happens in the process of creating, the expression of emotion and the personal insights attained. -Shawna Snyder, Acupuncturist (Synder, 2010, p. 1)

In the interest of this research the focus turns now to how these art programs are beneficial for cancer patients specifically. To start it is important to understand how cancer patients are affected by the diagnosis and treatment of cancer. Cancer-related fatigue, which interferes with usual functioning, is the most prevalent symptom for cancer patients; 75% of patients with various solid cancerous tumors had significantly increased fatigue scores compared to a matched control population (Bar-Sela, 2007). During chemotherapy treatment, fatigue symptoms can reach 100% of patients (Bar-Sela, 2007).

Along with fatigue comes emotional distress from treatment; 25% of cancer patients meet diagnostic criteria for major depression or anxiety disorders (Bar-Sela, 2007). These disorders cannot be considered 'normal' reaction and they have a severely detrimental effect of the patient's quality of life (Bar-Sela, 2007). Even after treatment the cancer survivor often describes two sides of survival – “one of celebration and hope, and one of uncertainty and fear.” (Yi, 2010, p. 1) Survival often includes late medical and psychosocial effects as well, such as post-traumatic stress symptoms, complications and disabilities (Yi, 2010).

'Integrative medicine' can help relieve many of these symptoms and stressors. 'Integrative medicine' is a synthesis of the best of cancer treatment and evidence-based, supportive complementary modalities that effectively relieve many of the physical and emotional

symptoms that cancer patients experience (Bar-Sela, 2007). “More than 80% of cancer patients may use some form of complementary therapy (or integrative medicine) in conjunction with other standard, medical treatment such as surgery, chemotherapy, and radiation” (Nainis, 2006, p. 162).

Some examples of integrative medicine include acupuncture, massage, naturopathy and music therapy. Art therapy is also one of the complementary therapies being used to relieve cancer symptoms. Art therapy is a clinical intervention based on the belief that the creative process involved in the making of art is healing and life enhancing. It is used to help patients increase awareness of self, cope with symptoms, reinforce positive coping behavior, increase their sense of control and adapt to stressful and traumatic experiences (Nainis, 2006). “It is the art itself that provides a vehicle for expression, aided by the actual physical movement of artistic materials. Art therapy may be preferential to some cancer patients who may be uncomfortable with conventional psychotherapy or those who find verbal expression difficult” (Nainis, 2006, p. 163).

It is important for the artist and art therapist to have some specialized training when working with cancer patients. Part of the training should involve learning and recognizing the four processes that a patient goes through during treatment, this is based on the End-of-Life Phase of Experiential Theory (Walsh, 2007). The first is “getting the news” and shock, followed by calculating the odds; the second is “dedicating resources” where focus is dedicated solely to the patient; the third is “negotiating treatment” which involves enduring stress as the patient fights for their lives, while shutting out negative feelings and maintaining hope; the fourth is “losing the battle” which occurs when the patient wants the suffering to end (Walsh, 2007).

Artists should be trained that these processes will be present as they interact with patients and their families.

For this research evidence was gathered to prove the effectiveness of these programs from a variety of studies. Within these studies a number of indicators were used by researchers to establish the effectiveness of these art programs for cancer patients. Most studies of these programs included: in-depth interviews, questionnaires of the patient before and after the art program, surveys addressing if they liked the program and suggestions for improvements of the program (Bar-Sela, 2007; Nainis, 2006; Singer, 2010; Walsh, 2007; Wood, 2010; Yi, 2010).

The in-depth interviews included questions about the patients' expectations, experiences with creative activities and types of psychological conflicts (Singer, 2010). The questionnaires included a selection of the following to determine the mental well-being of the participants before and after the art program: Hospital Anxiety and Depression Scales (HADS), Trier Coping Scales, Brief Fatigue Inventory (BFI), Edmonton Symptom Assessment Scale (ESAS), Beck Anxiety Inventory (BAI) or Spielberger State-Trait Anxiety Index (STAI-S) (Bar-Sela, 2007; Nainis, 2006; Singer, 2010; Walsh, 2007). These questionnaires established a base-line and a comparison to that base-line following the art program. At the end of the art program, or sometimes after each session, the patients were asked for input as to how the program could be improved, if they liked the session, and if they felt comfortable making the art (Nainis, 2006; Singer, 2010).

Outcomes of Art Programming for Cancer Patients

I felt unable to interpret my experience (with breast cancer) in a positive light. I struggled with this problem for years until I became aware that my health and happiness depended on my ability to transform my experience with breast cancer and surgery into something positive. (A plaster cast of my torso was made) The plaster cast made me think that I was broken and being reset in order to heal. Christiane (the artist) took our conversations and my plaster exoskeleton and created the sculpture *Night Light*. I find the sculpture honest, simple, comforting, quiet, strong, peaceful and filled with beauty. The magnitude of the changes I have been able to effect in my life since creating the sculpture astonishes me. I realize I am as happy and as optimistic as I have ever been. – Pamela Cruze, Breast Cancer Survivor (Cruze, 1998, p. 402)

The outcomes from these studies were significant, especially considering the relatively inexpensive interventions that entail an art therapist or artist's time and the cost of art supplies. One study found that of the 50 patients enrolled 88% had never done art therapy before, 96% felt comfortable making art, and 92% stated they would like to do art therapy again (Nainis, 2006). Along with patients willingness to creatively express themselves a marked improvement in mental well-being was measured.

First, **anxiety in patients was reduced significantly**. In one study of 69 family caregivers of patient with cancer; the mean score from the anxiety test (BAI) went from 7.28 to 2.49 (Walsh, 2007, p. E13). In another study of 23 cancer patients' anxiety dropped from 10.5 to 9.8, as measured by the Hospital Anxiety and Depression Scale (Singer, 2010, p. 367). And both physical well-being improved and emotional well-being improved; from 3.3 to 4.7, and 3.2 to 4.3, respectively (Singer, 2010, p. 367).

Second, **depression in patients was significantly lowered**. In a study of 19 cancer patients participating in a 4 session art program depression scores improved significantly from a base-line median score of 9.0 to 7.0, as measured by the Hospital Anxiety and Depression Scale (Bar-Sela, 2007, p. 982). In the same study improvements were also seen in the degree of fatigue, with a reduction from a median of 5.7 to 4.1, as measured by Brief Fatigue Inventory

(Bar-Sela, 2007, p. 982). These studies prove that the arts can be used for therapeutic interventions, as a way of transformation and healing. “It has been shown that patients who feel better about themselves and are more hopeful live longer with cancer” (Lane, 2006, p. 74).

The previously mentioned studies of art programs for cancer patients also explored best practices in regards to the structuring of these programs for patients. It was noted across the studies that a high level of structure is needed, especially in the beginning sessions of the art program, to give the participants a safe environment for self-exploration and expression, and reduce the insecurity about being creative (McCarthy, 2011; Singer, 2010). “The program should be structured and facilitated in a way that the group process is not allowed to negatively impact participants, and so patients don’t disclose too much too soon” (Heiney, 1999, p. 183).

Eventually as the program builds, step by step, the participants learn to work with less structure and develop their own system of structure and the program can become more self-exploratory (Singer, 2010). Finally, the creation of a final ‘object’ is especially important so the participants remain focused and can frame the program with an indicated end point (Singer, 2010). Additionally, creating an object can help patients regain a sense of control, “the creation of a book (or object) enables participants to regain control; a matter that is especially important for patients with cancer as a disease that can often make them feel like they have lost control” (Singer, 2010, p. 369).

There are many different objects the patient can create. The creation of a book or journal in particular helped participants “bundle” their thoughts or concerns into a unique expression (Singer, 2010). Scrapbooking is another ‘normal’ activity without the negative stigma that a support group may carry. Photovoice can also be used and allows patients to express their stages of recovery and “brings awareness to healing through the eye of the patient” (Snyder, 2010, p. 1).

Overall these studies found that the normalcy of an art program allowed patients to express themselves, while avoiding the stigmatizing nature of art ‘therapy’ or support groups or psychotherapy, many of which are avoided (Bar-Sela, 2007; McCarthy, 2011; Singer, 2010).

Creative interventions have been shown to shorten hospital stays and decrease the use of pain medication dramatically, (Lane, 2006) all while decreasing isolation and anxiety, strengthening psychological health and lowering depression in cancer patients (Heiney, 1999, p. 187; Walsh, 2007, p. E10). For these reasons many health care providers believe that art therapy can support the treatment of cancer patients (Bar-Sela, 2007).

This research highlights how artistically creative activities within healthcare institutions strengthen the psychological health of their patients and are proven therapeutic interventions that work. Therapeutic art programs used as integrative medicine are relatively inexpensive and highly effective. The overall emotional and physical benefits for patients have been evidentially proven again and again. The reduction in anxiety and lowering of depression alone is statistically significant. In addition patients have less pain, use less pain medicine, and are more hopeful. Overall the benefits to the quality of life for a patient, and specifically a cancer patient, are significant.

One indicator of the rise of arts-in-healthcare is the membership to the Society for the Arts in Healthcare which has more than doubled in the past five years. The field is now a mixture of healthcare institutions, artists, arts therapists, doctors, nurses, arts managers, architects, interior designer and others (Anagnos, 2004). Arts programs are becoming embedded in the work of hospitals which reflects the now widely accepted belief that the arts have a powerful effect on how we feel; and that the arts can promote the overall well-being of the patient.

Section II: Young Adult Cancer Survivors

Young Adult Cancer Survivors' Needs

The biggest stress I had going through all of this was information . . . I had to do a lot of my own research, a lot of my own searching for stuff. - Young Adult Cancer Survivor. (Rabin, 2011, p. 800)

In this chapter I am giving a contextual backdrop to the issues facing young adult cancer survivors. I am also providing evidence for the importance of cancer survivor camps for young adults. Within this context a young adult cancer survivor refers to anyone between the ages 18-39 years of age when diagnosed through to the rest of his/her life.

A young person being diagnosed with cancer is a nonnormative life event. For a young person going through cancer treatment can be especially traumatic, isolating and stressful. Nonnormative life events are unusual occurrences that are not normally anticipated and may have a major impact on development. The occurrence, pattern, and sequence of these events are not applicable to many individuals; “experiencing a chronic disease in early adulthood is a nonnormative event” (Fisher, 2005, p. 658).

Young adult cancer patients represent 5% of the total cancer population. According to the American Cancer Society (2010) 70,000 young adults, ages 18-39, are diagnosed with cancer each year. While survival rates for older adults and children have markedly increased, survival rates have not increased since 1975 for young adults (Hobson, 2007, p. 76).

A 10-year-old diagnosed with cancer in the late 1970's had about 60% chance of surviving for five years. But a 10-year-old diagnosed in the '90s odds upped to 75%. For 65-year-old, the five-year survival rate leapt from about 45% to more than 65%. Then consider a 30-year-old: While she had a 70% chance of living for five years back then, her prognosis had actually slightly worsened by the late 1990s. (Hobson, 2007, p. 76)

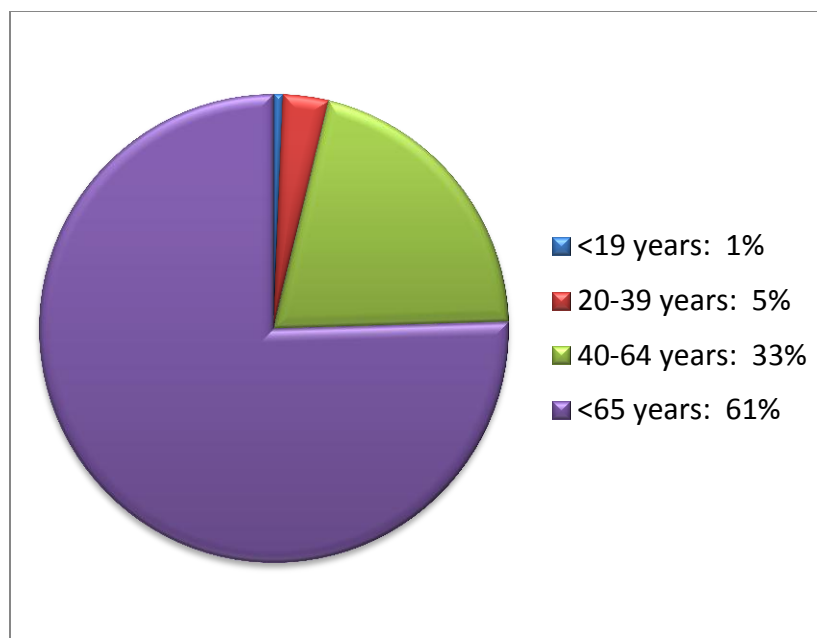


Figure 2: Percentage of Total Cancer Population by Age Group
Source: National Cancer Institute 2005

Young adult cancer patients represent 5% of the total cancer population. According to the American Cancer Society (2010) 70,000 young adults, ages 18-39, are diagnosed with cancer each year. While survival rates for older adults and children have markedly increased, survival rates have not increased since 1975 for young adults (Hobson, 2007, p. 76).

Due to the fact young adult cancer survivors make up only 5% of the total cancer population, isolation from other young adults experiencing the same nonnormative life event is likely. Isolation becomes a major factor for young adult cancer survivors while they battle cancer. As a young adult cancer patient myself, I know the feeling of walking into a cancer center with other patients 30 years my senior and being totally unable to relate to them. Our life stages were just too different. It was crucial for me to find a community of other young adult cancer patients/survivors in order to break through that isolation. I was lucky enough to be in a city where a Young Adult Cancer Survivor Support Group existed. Nationwide these groups are few and far between, even though Livestrong is currently working on ways to develop more.

This group of young adult survivors were the only community I could relate to while in the battle for my life. They understood my fears, my physical deterioration and my battle, because they were living it or had lived it themselves. This community of young adult survivors was integral for my emotional well-being as navigated this battlefield. These survivors became my comrades on that battlefield and the bond between us is and was unbreakable and indescribably deep.

In fact, isolation becomes a major factor for young cancer survivors while they battle cancer. Along with having cancer, the community the young person belonged to before cancer changes drastically. More often than not healthy friends disappear as treatments and the threat of death face the young cancer patient. This is evident in the words of one patient: “Friends don’t want to deal with your mortality. People don’t want to accept the idea that you can get something that can either kill you or can have a lasting impact on the rest of your life” (Pontius, 2008, p. 47).

This can make the cancer journey for young adults even more isolating and the need for psychosocial support increases as healthy friends fall away. In a survey of 20 young adult survivors 15 of the participants spoke of a need for greater emotional support throughout their cancer experience. The participants stated others who had not had cancer (family and friends) could not relate to the survivor’s experience. “I have people around me and just nobody understands what I’m going through” (Rabin, 2010, p. 800).

This research explores how young adult survivors without access to a local support group can connect to this community of young survivors in other ways and break through the isolation. “The experience of sharing stories and experiences with others who have been in similar situations can be enormously comforting and healing” (Zebrack, 2009, p. 352). One way young

survivors can connect is through cancer survivor camps. These camps are located nation-wide. One camp that is especially well-known for serving the young adult population is Camp Mak-A-Dream.

These nonprofit camps bring cancer patients and survivors together for week-long sessions. In many cases this will be the first time a young adult survivor will meet other young survivors. These safe, medically supervised, inclusive camps give participants the chance to bond, attend educational workshops and have fun. After these young survivors meet they often continue to connect as friends on Facebook continuing their community online. “Empathy, understanding and acceptance was the main benefit expressed to having a friend who also had cancer” (Martinink, 2003, p. 753).

Behavioral interventions for cancer survivors have historically targeted older adults or young adults of childhood cancers. In a survey of 217 young adult cancer survivors, three fourths indicated a need or desire for peer support programs. Ninety-five percent of those surveyed have used or want to use internet sites that offer cancer education or support that is appropriate for young adult cancer patients (Zebrack, 2009, p. 354). In a survey of 879 young adult survivors 62% wanted programs, such as camps or workshops, that offer cancer education and support appropriate for young adults (Zebrack, 2009, p. 352). These findings are important in guiding practitioners and program developers as to what type of programs of supportive cancer care are necessary in the future.

Young survivors desire to participate in programs with other cancer survivors their own age (given the rarity of incidental interactions with young survivors) and have an interest in and comfort with the internet as a vehicle for receiving cancer-related information and for connecting with other cancer survivors. (Rabin, 2011, p. 802)

In the survey of 879 young adult survivors the study pointed to the want for more programs on topics that deal with grief and loss, intimacy and dating, late effects (especially

fertility), mental health counseling, obtaining and maintaining health insurance coverage and self-improvement in the form of nutrition and exercise (Zebrack, 2005, p. 780). “The main intent of these programs is to instill skills and encourage survivors to apply at home what they learned at camp...” (Zebrack, 2005, p. 781).

Another important study concluded that for campers affective changes (improvements) were not present immediately after camp, but were quite significant when measured 4-6 months later. “Statistically significant improvements on negative mood and anhedonia and a significant decrease in overall depression scores were reported between pre-camp and follow up 4-6 months later for patient campers” (Wellisch, 2005, p. 4). This posits that campers reflect on the positive memories and the pleasure in camp activities over time.

This research has both marked a need for more programs for young adult survivors and shown the positive effects on children’s psychosocial well-being from participating in camp (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2005). Decreasing stress and enhancing coping strategies in young survivors during the adjustment of such a non-normative life event is crucial. The stressors are overwhelming for young survivors and these camps and their social support and programming have shown conclusively to help these young survivors in a myriad of ways.

Social support has been shown to decrease stress, calm and reassure survivors and helps teach them long-term coping strategies. Through document analysis of cancer survivor camp studies it is significant to note that these camps are proven effective in decreasing stress and enhancing coping strategies (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2006). Improving the quality of life for these young survivors through effective camp programming is important.

Young survivors desire to participate in programs with other cancer survivors their own age (given the rarity of incidental interactions with young survivors) and have an interest in and comfort with the internet as a vehicle for receiving cancer-related information and for connecting with other cancer survivors (Rabin, 2011, p. 802).

Raising awareness about these camps for young survivors is equally important. In a survey of 20 young adult cancer survivors 12 indicated they were not aware of programs for cancer survivors. Others indicated these programs were not well advertised. One young adult survivor stated: “I really had to do a lot of work myself to find out about things (resources) . . . but I don’t feel it should be that way, because your mind is clouded so much already, that those thing (resources) should just be available through your doctor of whatever and they’re just not” (Rabin, 2011, p. 801).

Psychological & Psychosocial Issues of Young Adult Cancer Survivors

This section explores psychological and psychosocial issues in the young adult cancer survivor population. To begin, prevalent psychological issues within the general cancer population will be explored. This will be followed by the examination of issues unique to the young adult cancer survivor population. Young adult cancer survivors (YACS) are between the ages of 18 and 40 when diagnosed. In this context, a cancer survivor represents any person from diagnosis onward through the rest of their life. The conclusion will address services that help YACS along with how to bring about post-traumatic growth in this population.

Life threatening illness has recently been recognized in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) as a trauma that can directly result in posttraumatic stress disorder (Kangas, 2002, p. 499). Research has shown that cancer is capable of generating symptoms that indicate posttraumatic stress disorder (Cella & Tross, 1986; Cordova, 1995; Andrykowski, 2000). Cancer causes loss, crisis, fear and anxiety, all of which are criteria of a major threat to health and life (Deimling, 2002, p. 479).

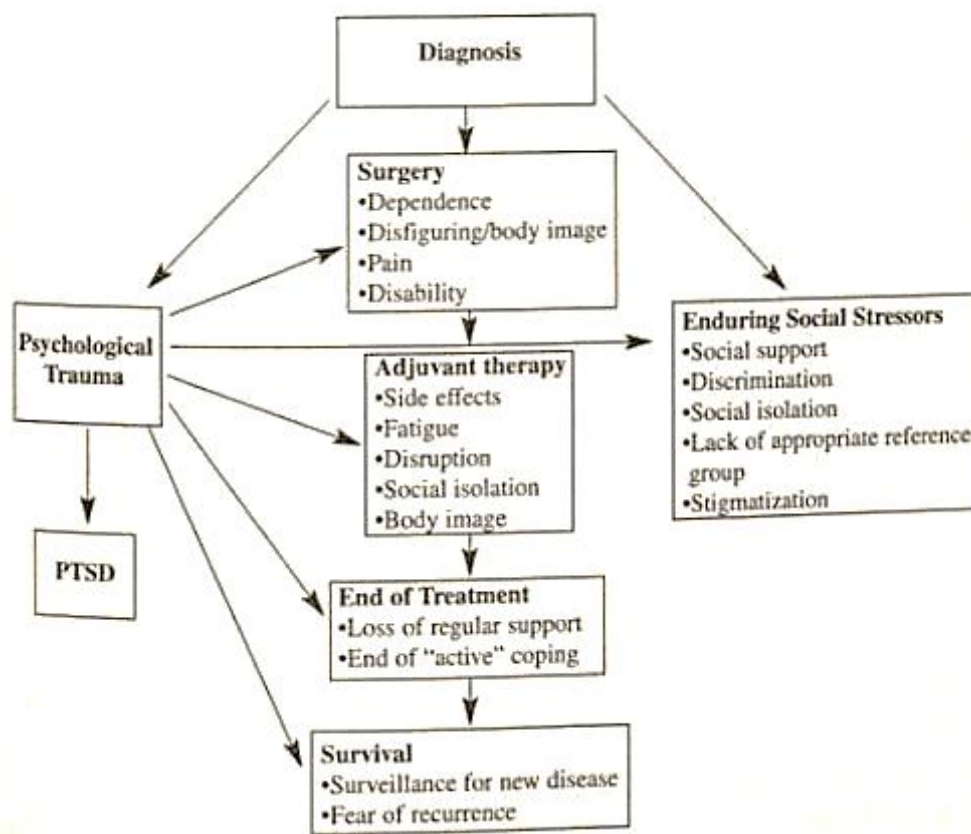


Figure 3: Aspects of cancer treatment that can cause psychological trauma, PTSD and enduring social stressors. Source: Suinn, R. M., & VandenBos, G. R. (1999). *Cancer patients and their families: Readings on disease course, coping, and psychological interventions*. Washington, DC: American Psychological Association.

Posttraumatic stress disorder (PTSD) is caused by exposure to, or witnessing of, a traumatic event that involved actual or threatened death and which invoked intense fear, helplessness or horror in the recipient. The individual experiences either intrusive memories, nightmares, a sense of reliving the trauma, or psychological and physiological distress when reminded of the event.

An individual with PTSD may experience avoidance of thoughts, feelings or reminders of the trauma and the inability to recall aspects of the trauma (constriction), withdrawal from others, emotional numbing (dissociation) or a sense of foreshortened future. Symptoms of PTSD

include: insomnia, irritability, concentration difficulties, hypervigilance, or exaggerated startle response (Kangas, 2002, p. 500).

The majority of studies on PTSD in cancer survivors suggest the prevalence rate ranges between 5% to 15% (Stein, 2008, p. 2584), while the base rate of PTSD in the general population is estimated to be in the range of only 1% to 4% (Stein, 2008, p. 2584). In terms of intrusive and avoidance symptoms, cancer patients have been found to report high rates of intrusion (16% to 43%) and avoidance (15% to 28%) symptoms (Kangas, 2002, p. 509).

PTSD in YACS affects between 12% to 16% of young survivors, which is higher than the PTSD lifetime prevalence of the general population (Mehnert, 2008, p. 389; Soliman, 2008, p. 59). However, on average a substantial portion (48%) of survivors report a range of PTSD symptoms (Holland, 2005, p. 2632) and more than half of patients experience their disease as a traumatic event and respond to it with intense fear, helplessness or horror (Mehnert, 2006, p. 186).

In a large survey of 1,083 cancer survivors; young survivors were found to have significantly higher levels of anxiety (7.22) compared to the normative control group (4.87) (Mehnert, 2008, p. 387). In a study of 450 YACS, major depression affected 15% of men and 22% of women (Soliman, 2008, p. 59). Cognitive behavioral therapy has been found to be only moderately effective in treating PTSD and no studies exist on treatment outcomes that evaluate the effectiveness of any type of psychological intervention for cancer-related PTSD (Kangas, 2002, p. 517).

Distress is considered an 'acute' effect of cancer diagnosis and treatment (Stein, 2008, p. 2582). Distress encompasses a variety of psychological responses, including depression and anxiety. Depression also affects this population with rates for clinical levels of depression

representing on average 25% (Deimling, 2002, p. 485). This is 3-fold to 4-fold that of individuals with no cancer diagnosis (Stein, 2008, p. 2584).

In addition, a relatively high number of patients who have major depression also suffer from cancer-related PTSD (Kangas, 2002, p. 517). This speaks to the comorbidity issues associated with the cancer condition. The comorbidity between PTSD and anxiety, depression, substance abuse, somatoform disorders and personality disorders is well documented (Kangas, 2002, p. 516).

Cancer diagnosis and treatment is considered a Type II trauma because patients are exposed to prolonged, repeated, or multiple stressful events during cancer treatment. Individuals exposed to Type II trauma exhibit greater PTSD symptoms compared to individuals who experience a Type I trauma, which results from a discrete, single event (Kangas, 2002, p. 513).

Most PTSD result from external events that pose an immediate threat, however cancer represents a protracted and internally based stressor that is ongoing (Kangas, 2002, p. 514). This is a key distinction from other traumas, as cancer-related trauma is a stressor that is triggered by an internally induced event rather than an external source of threat (Kangas, 2002; Green, 1998). This means the stressor cannot be physically avoided and is an ongoing event.

Although the stressor and the disease are both internal issues there are many studies that confirm that psychological symptoms, such as intrusion, depression and PTSD, do not predict disease progression of cancer within a patient (Cassileth, 1985; Jamison, 1987; Epping-Jordan, 1994). In fact, avoidance was the sole psychological marker of cancer progression, most likely due to a decreased compliance with cancer treatment, which would in turn lead to worse disease status (Epping-Jordan, 1994, p. 545).

Quality of Life Issues

What is clearly affected by a cancer patient/survivors psychological symptoms is their quality of life. In a study of 167,096 cancer survivors, it was determined that there is a sharp decline in both physical and mental health health-related quality of life scores for individuals recently diagnosed with cancer compared to those without cancer and longer term cancer survivors (Baker, 2009, p. 3031). In this study of a large sample of cancer patients, with an age-matched no-cancer control group, it was also determined that cancer survivors do not return to the same level of quality of life as those who have not had cancer, at least within the two year time frame studied (Baker, 2009, p. 3030).

Certain cancer populations are more vulnerable to quality of life issues due to cancer diagnosis and treatment (Baker, 2005; Kangas, 2002; Mehnert, 2007). In a study that identified the psychosocial problems of 752 cancer patients it was found that more problems were reported by younger survivors (ages 18-54 yrs), women, nonwhites, those who were not married, and those with a household income of less than \$20,000 a year (Baker, 2005, p. 2565). This population was found to have statistically significantly higher means for both the number of problems reported and the Cancer Problems in Living Scale total score (Baker, 2005, p. 2569).

Of the total population in this study more than 25% of adult cancer survivors at 1 year past diagnosis had problems including continued health problems, psychosocial problems, emotional discomfort, fears about the future, financial problems and difficulties in returning to former roles (Baker, 2005, p. 2575). More than two-thirds were concerned with their illness returning, nearly 60% were concerned about disease recurrence, and nearly 58% were fearful about their future (Baker, 2005, p. 2571).

It is important to note younger cancer patients (ages 18-54 yrs.) reported experiencing on average three more problems than older patients in this study (Baker, 2005, p. 2572). These problems include fertility issues, career choices/job discrimination, health insurance worries, financial needs, and feelings of vulnerability, isolation and helplessness (Baker, 2005, p. 2571). These additional problems are likely due to the fact younger individuals with cancer are more likely to still be employed and to have dependent family members and related concerns of an earlier life stage (Baker, 2005, p. 2572).

Several studies found that young, single cancer patients with poor social support and low income were also more vulnerable to psychological distress and PTSD responses (Baker, 2005; Kangas, 2002; Mehnert, 2007). In addition to the psychological distress of cancer treatment, more often than not betrayal trauma effects young patients as well, because their healthy friends disappear as treatments and the threat of death face the young adult cancer survivor.

Betrayal trauma is defined as "the biological, psychological, and/or sociological (biopsychosocial) harm caused by an actual or perceived violation of a psychological contract by person(s) upon which the victim relies for some aspect of his or her holistic well-being" (Hensley, 2009, p. 105). Betrayal trauma is thought to be more injurious than physical and other traumas because it destabilizes the mental model, schemas, and psychological contracts the victim has established to see, understand, and respond to life events, leading to extreme biopsychosocial distress (Hensley, 2009, p. 105). One young adult patient explained this abandonment: "Friends don't want to deal with your mortality. People don't want to accept the idea that you can get something that can either kill you or can have a lasting impact on the rest of your life" (Pontius, 2008, p. 47).

This betrayal trauma typically occurs at the beginning of treatment when YACS are very vulnerable and in need of more social support, not less. In one survey of 20 young survivors 15 had a desire for greater emotional support throughout their cancer experience (Rabin, 2010, p. 800). Alienation becomes prevalent, as those surveyed stated others who had not experienced cancer could not relate to the survivor's experience (Rabin, 2010, p. 800).

Benefits of Peer Support

Meeting other young adult cancer survivors becomes a top priority for a young cancer patients. In a study of 40 young adult cancer patients, 100% ranked opportunities to meet other survivors as a top 5 need, whereas only 50% ranked support from family and friends as a top 5 need (Zabrack, 2006, p. 2922). The majority of YACS (young adult cancer survivors) emphasize a desire to participate in programs with other cancer survivors their own age (Rabin, 2010; Soliman, 2008; Zebrack, 2006; Zebrack, 2009).

It may be surprising that peer support from other young adult cancer survivor has ranked greater than the importance of support from family and friends (Zebrack, 2006, p. 2922). Yet socially connecting with other young adult survivors from a developmental perspective may help them learn new coping skills while connecting with others who have had similar life experiences (including social exclusion/alienation) (Zebrack, 2006, p. 2922).

Post-traumatic growth in young adult cancer patients and survivors has been found to come from social support and adopting appropriate coping strategies to endure stress (Love, 2011, p. 279). Post-traumatic growth is generally defined as the positive psychological change that emerges following significantly difficult, or traumatic, life events and has been characterized by an increased appreciation for life (Love, 2011, p. 278). In fact, more advanced stages of

cancer have been related to higher experiences of posttraumatic growth (Love, 2011, p. 282). This supports the idea that growth follows more extensive trauma (Tedeschi, 1996, p. 455).

Peer support programs can be offered in the form of retreats, workshops, support groups, camps. All of these forms help promote a sense of group identity and shared experience important for development for this age group (Zebrack, 2006, p. 2922). Overall other forms of intervention social support was found to be a significant predictor of psychological growth (Love, 2011, p. 278). Those who have found positive meaning in their cancer experience were able to buffer the negative impact of intrusive thoughts (Park, 2009, p. 1143).

In a majority of studies, peer involvement between young adult cancer survivors was emphasized as a top priority for learning how to cope with unique concerns specific to their stage of life (Evan, 2006; Soliman, 2008; Zebrack, 2006). Concerns within this age group include: coping with the uncertainty of recurrence, forced dependence on others, social exclusion, body image, adult relationship issues, sexuality and fertility, financial concerns and career issues (Evan, 2006, p. 1667; Zebrack, 2006, p. 2922). It is important to note that these concerns and psychological stressors are significantly different from those of adolescent or older cancer survivors (Evan, 2006, p. 1667).

Across the studies, the overall benefits from peer support participation was conflicted. In one study although the psychological well-being improved for YACS participating in support group interventions, changes in coping mechanisms and overall quality of life did not improve (Roberts, 1997, p. 133). In another study, the likelihood was greater for young adult patients to participate in support groups and 78% of those who participated reported it had been beneficial (Owen, 2007, p. 2585). In another, 45-64 year olds had a higher likelihood of utilizing support

groups compared to YACS (Owen, 2007, p. 2584). This may be due to the fact very few young adult cancer survivor support groups exist for this age demographic nation-wide.

The Livestrong Young Adult Alliance is working to create more young adult cancer programs nation-wide and comprehensive cancer centers should follow suit. The development of care for the YAC population still needs to be undertaken at a majority of cancer centers (Soliman, 2008, p. 60). Also, more research is needed in assessing the benefits from these peer support programs to determine their effect on the quality of life for young adult cancer survivors (Zebrack, 2006, p. 2916).

Peer support programs can be offered in the form of retreats, workshops, support groups, camps. All of these forms help promote a sense of group identity and shared experience important for development for this age group (Zebrack, 2006, p. 2922). Overall other forms of intervention social support was found to be a significant predictor of psychological growth (Love, 2011, p. 278). Those who have found positive meaning in their cancer experience were able to buffer the negative impact of intrusive thoughts (Park, 2009, p. 1143).

In closing with this section, it is important that further research on the effectiveness of peer support interventions and other psychological interventions for young adult cancer survivors be explored. Research designed to enhance well-being in cancer patients and survivors is still in its infancy (Stein, 2008, p.2587). In addition, the YAC population is understudied overall. This field will benefit from future research on the influence of peer support on adjustment and coping of young adult cancer survivors (Evan, 2006; Love, 2011; Soliman, 2008; Zebrack, 2006).

Section III: Cancer Camps

This section of the literature review reveals the need for more programs for young adult survivors and the positive effects on children's psychosocial well-being from participating at cancer camp (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2005).

Overview of Cancer Camps

In the past two decades, more children have survived cancer and other chronic illnesses, and the role of camps has evolved. This has been attributed to the shift in medical prognosis for these children, from certain death to a more chronic illness (Pinkel, 1976). This shift to survivability has led to a shift in psychological emphasis from crisis intervention and confronting death, to making adjustments to surviving a chronic disease.

The improved rates of survival for those diagnosed with childhood cancer in the 1970's led to the establishment of the first summer camp for children with cancer in Florida, in 1976 (Martiniuk, 2003, p. 750). This first camp was established as part of a psychosocial rehabilitation program for pediatric cancer patients. During the 1970's and 80's more than 60 camps were established in the USA, specifically for pediatric cancer patients (Bluebond-Langer, 1991).

Currently, there are 76 camps that provide children with cancer a camp experience (Children's Oncology Camping Association, 2002). Although all of these camps are for children cancer survivors there is a wide variation in terms of activities, events, staff characteristics, duration of session, size and location. Campers come from a wide geographic area and from many treatment centers to attend camp as a part of psychosocial rehabilitation.

Effect of Camp on Young Survivors

In stark contrast to these 76 camps for children, to date there are only 6 camps or retreats for young adult cancer survivors. Due to the large numbers of these camps for children there have been a substantial number of studies on Cancer Camps for Children (Pediatric) Cancer Survivors. In addition, due to the small number of camps for young adults, there have been very few studies on Cancer Camps for Young Adult Cancer Survivors. Therefore, to better understand the benefits of these camps, focus was placed on studies done examining the effects of camps for children cancer survivors. A majority of these studies report the effects of camp on the quality of life for children with cancer. They have conclusively shown the positive effects on children's psychosocial well-being from participating in camp (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2005).

In one peer-reviewed article, that included a literature review of nine studies, entitled *Camping Programs for Children with Cancer and Their Families* four of these studies found that children experienced more positive mood states, were more physically active, and engaged in significantly more social activity post-camp (Martiniuk, 2003, p. 752-3). Also in these four studies, it was noted that while at camp children engaged in informal discussions with their peers about cancer, and established relationships with fellow campers that lasted beyond camp (Bluebond-Langer, 1990; Bluebond-Langer 1991; Kessel, 1985; Smith, 1987).

Another study of the psychosocial impacts of cancer camp for children with cancer showed that overall depression scores significantly decreased, along with improvements in negative mood (Wellisch, 2005, p. 4). It is interesting to note in this study that the improvement in overall affective symptoms for the 31 children cancer camp participants was not present immediately after the camp experience, but was quite significant when measured 4-6 months

later (Wellisch, 2005, p. 9). Therefore, the benefits from experiencing camp for these children became more pronounced, not just sustained, over time.

Rehabilitation involves social and peer relationships, which are key in the return of pediatric cancer patients to a healthy pattern of living (Katz, 1980). In fact, it has been found that the more quickly children can resume normal activities, including social and family activities, the better the long-term adjustment (Koocher & O'Malley, 1981).

Camp Programming

These camps for children with cancer came into existence to improve the participant's quality of life through recreation and leisure. The theory that recreation serves important functions is not new. Freud in 1955, Erikson in 1963, and Bolig in 1980 wrote about recreation and its role in helping children master anxiety-producing events to help them learn to cope with experiences, thereby contributing to quality of life (Martiniuk, 2003, p. 750).

Typical goals in camp programming include: improving quality of life, developing emotional stability, increasing interpersonal/social skills, developing feelings of competence, increasing feelings of belonging, decreasing stress, improving physical fitness, self-efficacy, perceived control, pleasure, enjoyment, and developing positive self-esteem (Crawford, 2001; Barnett, 1988; Ben-Arieh, 2001; Briery, 1999; Chung, 2000; Martiniuk, 2003).

Ultimately "learning new skills at camp increases (children's) confidence and improves their self-image, giving them a greater sense of control and responsibility in their lives" (Martiniuk, 2003, p. 750). Previous research hypothesizes that camp improves the psychosocial adjustment of its participants through its role as a social support (LaGreca, 1992; Martinson, 1990; Murray, 2000). One major benefit of this peer social support was the ability for campers

to experience empathy, understanding and acceptance from having a friend who also had cancer (Bluebond-Langer, 1991).

One distinct difference between children and young adult cancer survivors is that there are far more studies on children with cancer than on young adults with cancer. This focus on pediatrics spreads wide over the majority of studies from clinical trials and their availability to support programs and help for the family.

In addition, quality of life issues during and after cancer therapy have mainly been focused on children, not young adults. “Very few studies have been performed on the quality of life in young adult cancer patients and survivors. The overall paucity of quality of life data in such survivors is another manifestation of the general neglect of this age group” (Bleyer, 2002, p. 9). This lack of research on young adult cancer survivors directly impacts the number of programs available to young adults’ verses children. “Although young adult cancer survivors face increased medical and psychosocial risks, this population has not yet been the beneficiary of behavioral or psychosocial intervention programs” (Rabin, 2011, p. 796).

“Supportive programs need to be developed for health care professionals to address the isolation and identity transition needs of adolescent (and young adult) cancer survivors” (Jones, 2011, p. 1033). To date there are six camps or retreats for young adult cancer survivors. This number pales in comparison to the 76 camps for children cancer survivors. This is considerably more shocking when you consider there are five times more young adult cancer survivors than childhood cancer survivors.

There are distinct differences when discussing issues faced by these two age groups. One is the role of the parents and issues of autonomy. Parents may tend to overly protect the child which may result in social withdrawal and feelings of isolation and may lead to an increase in

solitary activities (Cairns, Clark, Smith, & Lansky, 1979; Koocher & O'Malley, 1981). Another distinct difference is that some camps for children with cancer have formal sessions about cancer to help children understand more about their illness while other camps have chosen to emphasize fun, age-appropriate activities (Hvizdala, Miale, & Barnard, 1978). In camps for young adults programming that involves discussing cancer is the norm.

The greatest difference in the management of young adult patients is in the support, particularly psychosocial care that they require. These patients have special needs that are not only unique to their age group but also broader in scope and more intense than those at any other time in life. The challenges include autonomy and independence, peer pressure, education, social development, intimacy, marriage, reproduction, fertility, employment, parenting and insurability. (Bleyer, 2002, p. 5)

One important aspect both children and young adult cancer survivor camps do have in common is the lack of information on, or the evaluation of, the effectiveness of these programs to meet goals of continued social, emotional and cognitive development (Balen, 1996; Epstein, 2005; Martiniuk, 2003). In 1998, the American Cancer Society Task Force on Children and Cancer reported that “The progress achieved in attaining 80% survival among children and adolescents and young adults with cancer can be justified ONLY if their physical, emotional, and social quality of life also are protected” (Haase, Maure, & Reaman, 1998, p. 822).

Quality of life after cancer is a function of social, emotional and behavioral processes involving adaptation to the issues imposed over time by the concrete physical and social realities of the disease (Zebrack, 2003, p. 16). Yet the validity, reliability and utility of instruments that measure quality of life in childhood cancer survivor populations has yet to be established and no gold standard for assessing “quality of life” in survivors of childhood cancer currently exists (Zebrack, 2003, p. 4). “Psychosocial and behavioral determinants on outcomes in young survivors is needed as a basis for the development of appropriate support programs throughout a

continuum of care, from diagnosis through treatment and over the long-term” (Zebrack, 2003, p. 14).

One clear similarity of the benefits of these camps for young survivors, no matter the age, is the positive effect of peer relationships. Overall the studies show that young survivors found their friends with cancer to have a greater understanding and empathy than their healthy friends, who were less able to offer support, hope and encouragement. Being able to interact with other survivors their own age, whether they were children or young adults, allowed them the ability to learn coping strategies that helped reduce fear and anxiety (Balen, 1996; Bluebond-Langer, 1991; Epstein, 2005; Evan, 2006; Smith, 1987; Soliman, 2008; Wellisch, 2005; Winfree, 2002; Zebrack, 2006).

“The experience of sharing stories and experiences with others who have been in similar situations can be enormously comforting and healing” (Zebrack, 2006 p. 782). So although cancer patients experience a common set of life disruptions, they experience them differently, focus on different issues and attach different levels of importance to different aspects depending on the time in life they were diagnosed (Zebrack, 2011, p. 2289).

Program Evaluation

Evaluating these camp programs for effectiveness is very important. However, investigators and healthcare providers have yet to test interventions that may promote positive psychosocial adjustment and the adoption of health promoting behaviors, and/or prevent negative outcomes and health risk behaviors at various points throughout the life span (Zebrack, 2003, p. 14).

Measuring programs effectiveness relies on evaluation tools that include: gathering feedback from program participants, interviewing specialists in the field, observation of program

participation and document analysis of previous programs. In this research the data collection instruments included a survey that used semi close-ended questions and interviews that used open-ended questions.

A non-experimental, qualitative descriptive design was used to evaluate the young adult cancer camps programs. The goal was to gather qualitative descriptive data about these programs, how they work, their effectiveness and the benefits of these programs for camp participants.

Qualitative methods are well suited for describing and assessing programs through a naturalistic approach (Brown, 2002; Davidson, 2005; McDavid & Hawthorne 2006). The human experience is emphasized as a way to collect narratives and gather subjective materials through observation, interviews and document analysis. Qualitative methods are especially useful when the objective is to obtain a holistic, comprehensive analysis of a program within the context of its implementation (Brown, 2002; Patton, 1987). The holistic perspective assumes the whole is greater than its parts. Qualitative methods are useful in rating the effect of a program and its usefulness (Davidson, 2005, p. 157).

The use a survey, interviews, recorded observations of participation and document analysis are a way to establish four different lines of evidence to elicit information about the program's effectiveness (McDavid & Hawthorne, 2006, p. 156). This triangulation of evidence from different points of view helps establish credibility of this research. This research is also based on the use of "Shoestring Evaluation" which recognizes that in many evaluation situations, the most appropriate methodologies are just not feasible due to budget restrictions (Bamberg, Rugh, Church, & Fort, 2004).

A general rule that should govern all data analysis is to employ the least complex method that fits the situation (McDavid & Hawthorne, 2006, p. 33). Assessing program effectiveness is the most common reason to conduct program evaluations. The effectiveness of programs in this research is measured in its ability to decrease anxiety; help with coping strategies and help survivors gain a sense of belonging and lower feelings of isolation.

Figure 4 depicts how a program fits within the environments of need to meet objectives. It is imperative to measure actual outcomes of programs to see if in fact they are effective.

We want to know whether, and to what extent, the program's actual results are consistent with the outcomes we expected. Are the observed outcomes consistent with the intended outcomes and the intended objectives? Did the program cause the observed outcome? Are the program objectives addressing the need that motivated the program? (McDavid & Hawthorne, 2006, p. 16-9).

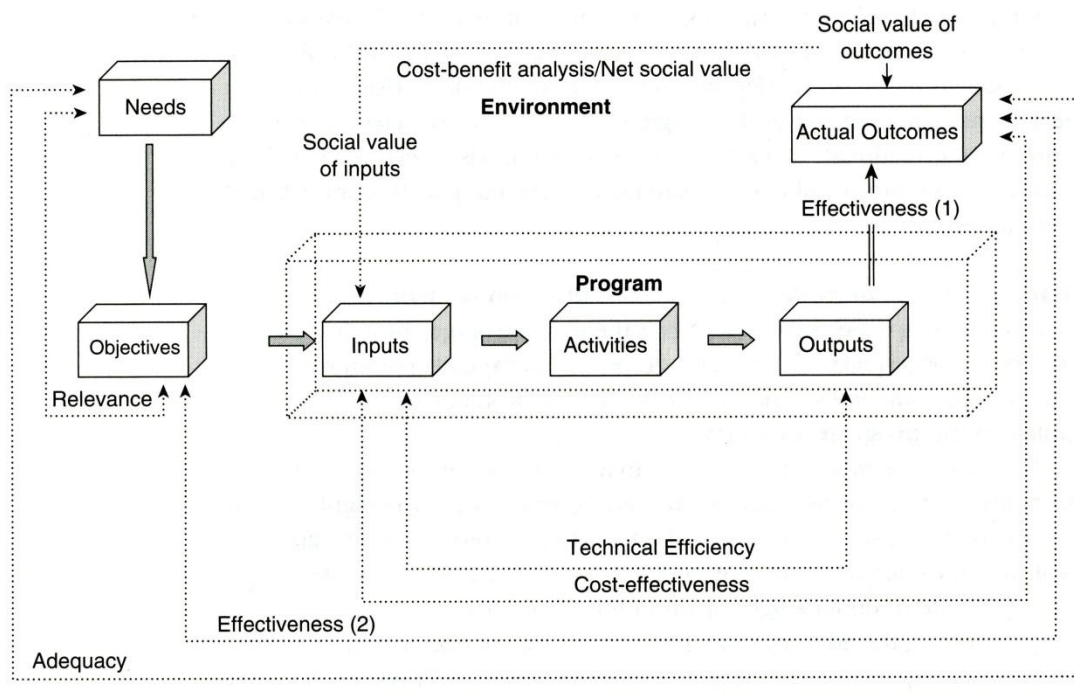


Figure 4: A visual model of the environment that drives programs. Source: Adapted from Nagarajan, N. & Vanheukelen, M. (1997). Evaluating EU expenditure programmes: A guide (p. 25).

Chapter IV: Data Collection, Analysis & Findings

Data Collection

Findings from this study were gathered from document analysis of previous surveys, charted observations of program participation, interviews of camp administrators, and a survey of young adult cancer survivor camp participants. The use a survey, interviews, recorded observations of program participation and document analysis are a way to establish four different lines of evidence to elicit information about the program's effectiveness (McDavid & Hawthorne, 2006, p. 156). This triangulation of evidence from different points of view helps establish credibility of this research.

The purpose of this study was to address the gap in literature regarding cancer camp programming and its effectiveness for young adult cancer survivors. This research collected data through reflective journals that charted the percentage of camp participants engaged in camp programs (collected in my role as a program facilitator), interviews of camp administrators as key experts in the field and an online survey of young adult cancer survivors about camp programming and its effectiveness.

Data Analysis

Overall, there is a lack of knowledge about these camp programs, specifically in regard to descriptive assessments to gain the perspective of young adult cancer survivor camp participants. An online survey of young adult cancer camp participants was used to gain their descriptive assessment of camp programs effectiveness. This data further addresses the gap in the literature by directly surveying young adults about what programming they find effective.

Findings

One of the key findings from this collected data was the importance of young adult cancer survivors meeting other YACS their own age. Their ability to meet and connect with

their peers within these programs helped with their psychosocial rehabilitation. The studies on psychosocial support needs of young adult cancer survivors support these findings (Rabin, 2010; Soliman, 2008; Zebrack, 2006; Zebrack, 2009). A key finding in the survey was that young adults want to participate in programs with one another for peer support.

The reason young adult cancer survivors attend cancer camp:

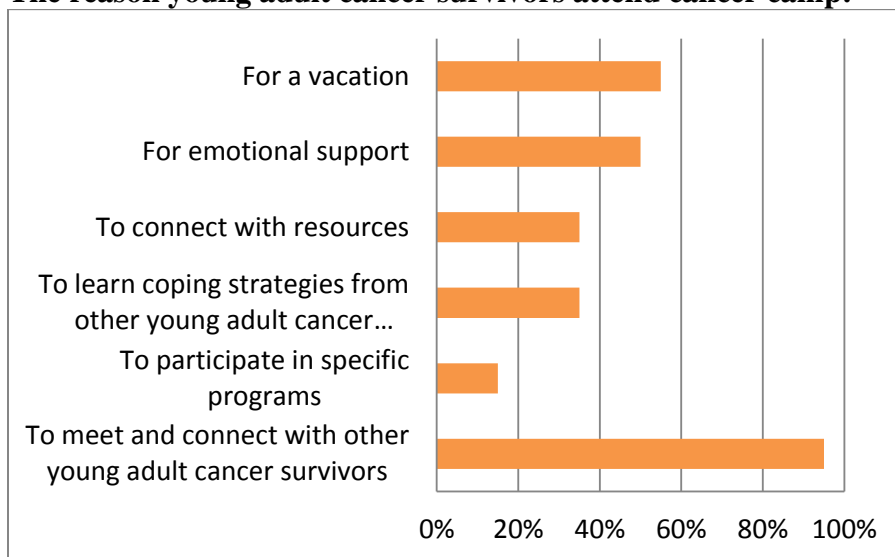


Figure 5: Reason's why young adult cancer survivors attend camp.

Source: Online survey of young adult cancer survivor camp participants.

Question: Why did you find a specific program to be the most engaging?

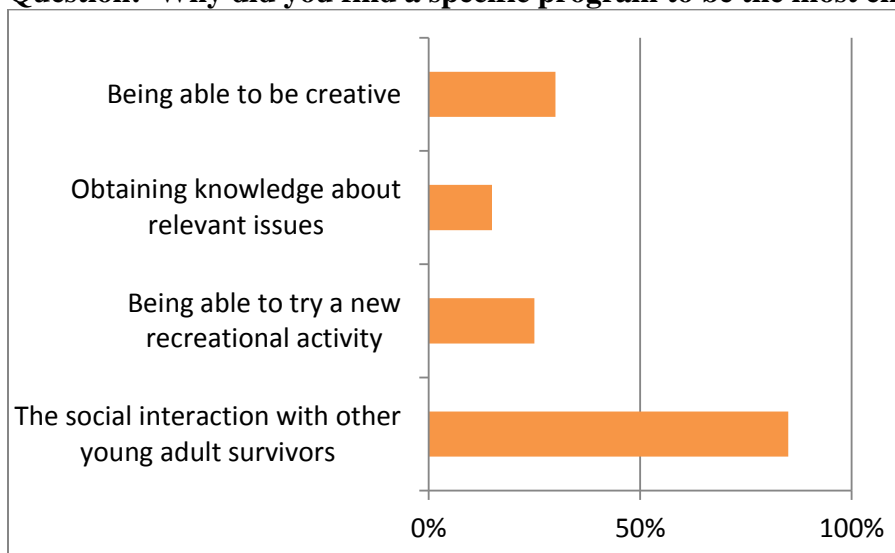


Figure 6: Answer to the question: Why did you find a specific program to be the most engaging? Source: Online survey of young adult cancer survivor camp participants.

Previous to this survey no one had asked these young adult camp participants what programming they found the most engaging and effective at camp. This survey was posted on two national cancer camps' Facebook pages of young adult cancer survivor participants to fill out. Twenty young adult cancer camp participants participated in the survey. The response overwhelmingly shows, by 95%, that young adults attend camp to meet and connect with other young adult cancer survivors. And 85% of young adults find programs engaging when there are social interactions with other young adult cancer survivors.

One survey question asked: As a young adult cancer survivor camp participant, what programs have you found to be the most effective and engaging at a cancer camp? 95% replied social interaction such as evening campfire discussions and cabin discussions were the most engaging programs; 70% said recreational activities and 45% stated art and educational activities were the most engaging.

It is important to note that in four separate survey questions the response shows that 85-95% of young adults are most engaged in programming that involves meeting and connecting with other young adult survivors in social interactions and discussions. When asked: Specifically how have you benefited from attending and participating in cancer camp programming, 95% stated they benefited from camp through connecting with other young adult cancer survivors. "The experience of sharing stories and experiences with others who have been in similar situations can be enormously comforting and healing" (Zebrack, 2009, p. 352).

Camp administrators are experts in the field and work tirelessly to bring high-quality programs to young adult cancer survivors. They understand the importance of these programs from seeing these programs at work first-hand. When asked what programs are key at camp for young adults the response from these camp directors was:

“The social interaction time where they can open up and share and express themselves freely. The most engaging programs are the recreational activities that allow for movement and are not too structured. This allows for freedom and fun.”

–Beth Jones, Camp Director for Camp Mak-A-Dream.

“Well it is a combination of recreational activities that allow young adults to interact on a peer level and the small group chats that allow them to share their experience with cancer.” – Meg Keigley, Program Director for Camp Mak-A-Dream.

A second key finding from the data is that there are very few programs available to young adult cancer survivors overall. This includes programs at camps, retreats, cancer clinics or hospitals. In fact, some of the only places these programs exist for young adult cancer survivors are at cancer camps. This can truly be measured in the fact that there are 76 camps for pediatric cancer survivors and only 6 camps or retreats for young adult cancer survivors. This is even more shocking when one considers that pediatric cancer survivors make up only 1% of the total cancer population and young adults make up 5 times that amount nationally.

What is all the more important to consider is how these programs are not being offered at cancer clinics or hospitals for young adult cancer survivors. These programs are paramount within a clinical setting due to the lengthy, extensive, aggressive treatment that young adults endure. In 1998, the American Cancer Society Task Force on Children and Cancer reported that “The progress achieved in attaining 80% survival among children and adolescents and young adults with cancer can be justified ONLY if their physical, emotional, and social quality of life also are protected” (Haase, Maure, & Reaman, 1998, p. 822).

It is clear from this study that hospitals and cancer clinics have failed to provide the emotional and social support that is fundamentally necessary for a better quality of life for this population. Even the most basic of programming, such as cancer survivor support groups are a rare offering for this population. To better understand the needs of these young adults I researched previous surveys. In a survey of 217 young adult survivors their need for several

programs was measured: 75% had a need for more peer support programs; 95% wanted internet sites that were geared toward young adults; and 62% wanted programs, such as camp or workshops that offer education and support (Zebrack, 2009, p. 352-4).

Cancer camps should not be held responsible for providing supplemental programming that these healthcare settings do not. Currently, however, this is the role that these cancer camps are playing. Key programs that camps do currently provide address emotional support, coping strategies & connection to resources.

Question: Within these programs at camp what topics (or subject matter) did you really appreciate being able to discuss?

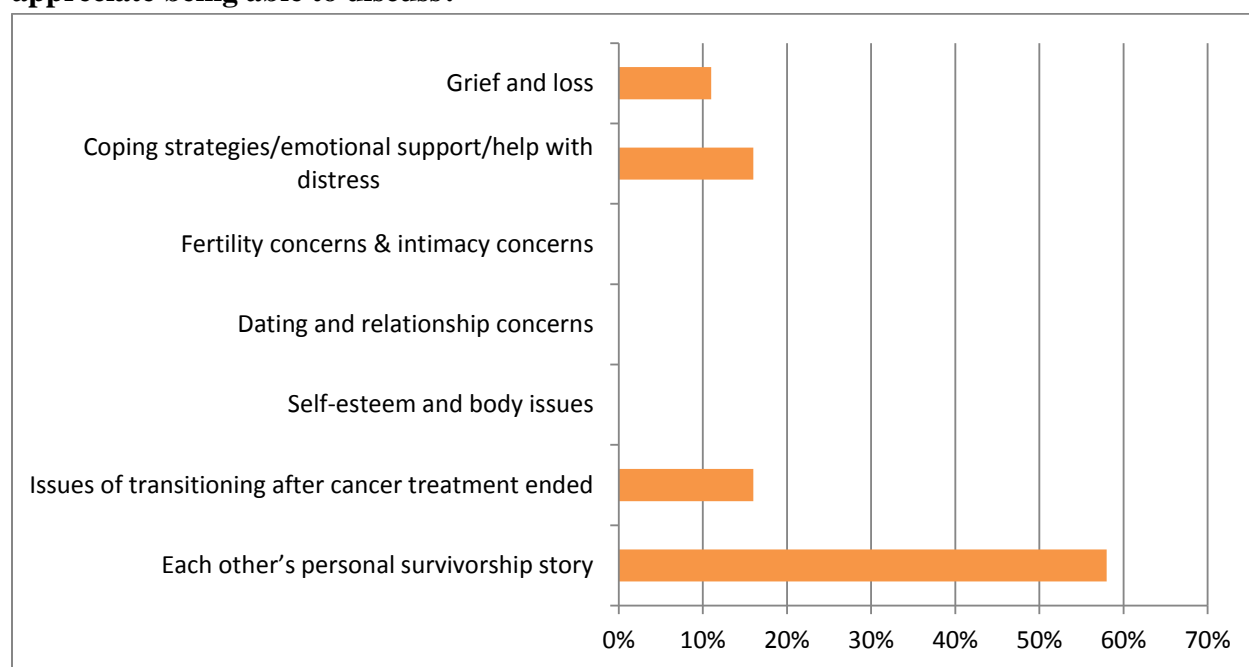


Figure 7: What topics within these programs did YACS really appreciate being able to discuss?

Source: Online survey of young adult cancer survivor camp participants.

There is still a gap in the kinds of programming that young adults need or desire from cancer camps. Although they have the opportunity to meet and connect with one another they are hoping for programs in the future that addresses topics such dating, self-esteem and fertility and grief and loss. Currently there are few programs that address these issues.

Question: In the future, within these programs at camp what topics (or subject matter) would you really appreciate being discussed?

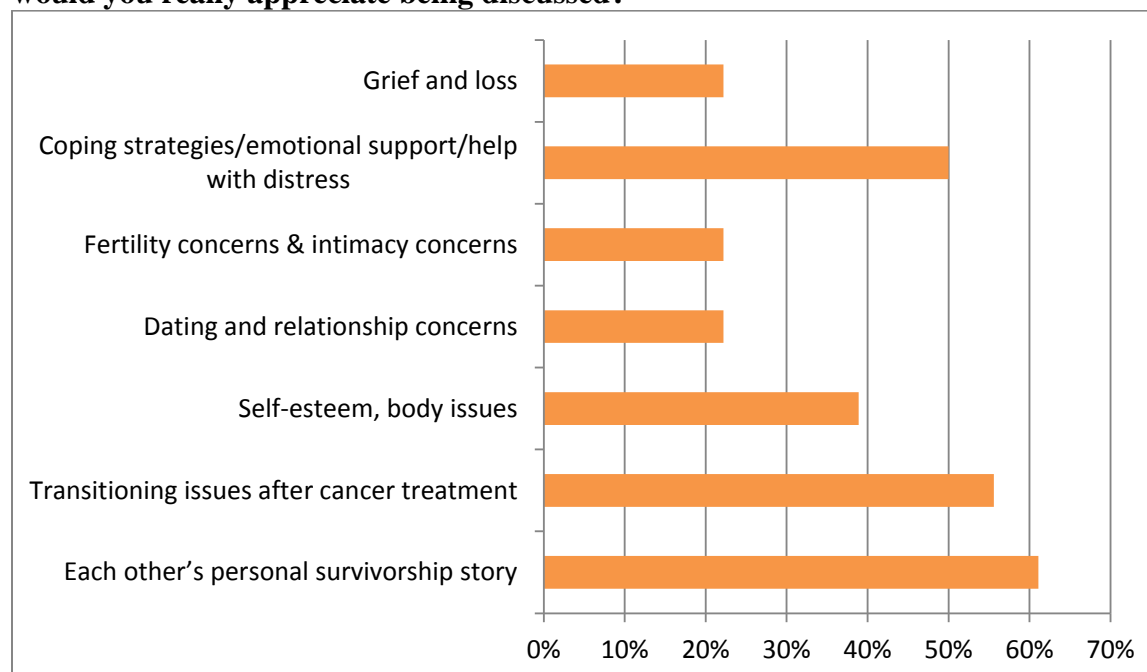


Figure 8: Question: In the future, within these programs at camp what topics (or subject matter) would you really appreciate being discussed? Source: Online survey of young adult cancer survivor camp participants.

It is especially clear that young adults hope to have programs that help with transitioning beyond cancer as indicated by a 55% need. Currently only 16% stated they participated in this type of program. This information on what types of programs YACS benefit from most can be a useful tool as camp directors and hospital program directors develop programming.

The overall goal of camp administrators is to bring programming to the camp session that is engaging and beneficial. As stated by Beth Jones, Camp Director of Camp Mak-A-Dream:

“The most important goal is to have a safe, supportive environment. A protective bubble where they can gain the tools they need that can carry with them beyond camp. Whether that be confidence, medical information, or finding friends they can continue to connect with virtually. Also giving them tangible pieces of information to walk away with is very important. The overall goal (of camp) is to help improve the quality of life beyond camp for these survivors. And that quality of life piece is unique to each person” (Beth Jones, Camp Director for Camp Mak-A-Dream).

Tonia Farman, Founder and Director of Athletes for Cancer talks more about the importance of improving the quality of life for these camp participants:

“Survivors leave camp with a new sense of direction and confidence and a new attitude. We are working on how to make a long-lasting impact, not just going about daily life; Thriving as individuals with a healthy mind and body. We want them to take this attitude into everyday life” (Tonia Farman, Founder & Director of Athletes for Cancer).

In my role as a program facilitator I was able to chart program participation by young adult cancer survivors. 80% participated in daily cabin chats, confidential small-group chats offered each afternoon. 85% attended fireside chats, a larger confidential group chat offered nightly. These two programs were the most popular and were offered more frequently than any other program at camp. This along with two main programs which included a talk by Johnny Immerman about how to connect with other young adults and a documentary about young adults participating in an adventure camp were the programs with the most participation.

The last chapter, Chapter V, will summarize and discuss this research and its findings. This will be followed by implications and recommendations for further development of programs and research for young adult cancer survivors.

Chapter V: Summary & Discussion

Summary

This research included an extensive literature review divided into three sections. The first section was an overview of arts in healthcare, which focused on art programming for cancer patients of all ages, and the benefits of these programs. The second section was an analysis of young adult cancer survivors; their needs, psychological and psychosocial issues, quality of life issues and the benefits of peer support for psychosocial rehabilitation. The third section was dedicated to the study of cancer camps; their history, programming and the effect of camps on young cancer survivors.

Following the extensive literature review data was collected and analyzed. Data collection methods included: observations of camp program participation; an online survey of young adult cancer camp program participants; informal interviews of camp administrators; and document analysis of studies previously conducted of this population. This strategy of inquiry was utilized to answer the questions: What are the benefits of cancer survivor camps for young adults? What programs/art programs are effective? How do these camps improve the quality of life for young adult camp participants?

Findings from the data analysis conclusively show that young adult cancer survivors engage in programs to meet other YACS. The survey for this research showed that 95% of young adults attend camp to meet and connect with other young adult cancer survivors. In fact, in four separate survey questions the response showed that 95-85% of young adults are most engaged in programming that involves meeting and connecting with other young adult survivors in social interactions and discussions.

The literature review of the psychosocial support needs of young adult cancer survivors also concluded that a majority of YACS emphasize a desire to participate in programs with other

cancer survivors their own age (Rabin, 2010; Soliman, 2008; Zebrack, 2006; Zebrack, 2009). In fact, in a majority of the studies, peer involvement between young adult cancer survivors was emphasized as a top priority for learning how to cope with unique concerns specific to their stage of life (Evan, 2006; Soliman, 2008; Zebrack, 2006). This was additionally supported by studies on cancer survivor camps which concluded that these camps are effective in decreasing stress and enhancing coping strategies (Balen, 1996; Epstein, 2005; Smith, 1987; Wellisch, 2005; Zebrack, 2005).

Discussion

Decreasing stress and enhancing coping strategies for young adult survivors during the adjustment of such a non-normative life event is important. Certain cancer populations are more vulnerable to quality of life issues due to cancer diagnosis and treatment (Baker, 2005; Kangas, 2002; Mehnert, 2007). Young adult cancer patients (ages 18-54 yrs.) reported experiencing on average three more problems than older patients in this study (Baker, 2005, p. 2572). These problems include fertility issues, career choices/job discrimination, health insurance worries, financial needs, and feelings of vulnerability, isolation and helplessness (Baker, 2005, p. 2571). These additional problems are likely due to the fact younger individuals with cancer are more likely to still be employed and to have dependent family members and related concerns of an earlier life stage (Baker, 2005, p. 2572).

In addition, several studies found that young, single cancer patients with poor social support and low income were also more vulnerable to psychological distress and PTSD responses (Baker, 2005; Kangas, 2002; Mehnert, 2007). In addition to the psychological distress of cancer treatment, betrayal trauma affects young patients as well; their healthy friends often disappear as treatments and the threat of death face the young adult cancer survivor.

Additional concerns within this age group include: coping with the uncertainty of recurrence, forced dependence on others, social exclusion, body image, adult relationship issues, sexuality and fertility, financial concerns and career issues (Evan, 2006, p. 1667; Zebrack, 2006, p. 2922). It is important to note that these concerns and psychological stressors are significantly different from those of adolescent or older cancer survivors (Evan, 2006, p. 1667).

However, programs that address these concerns are almost nonexistent. In a survey of 879 young adult survivors the study pointed to the want for more programs on topics that deal with grief and loss, intimacy and dating, late effects (especially fertility), mental health counseling, obtaining and maintaining health insurance coverage and self-improvement in the form of nutrition and exercise (Zebrack, 2005, p. 780). In the survey findings for this research it was concluded that there is still a gap in the kinds of programming that young adults need or desire from cancer camps. Although they have the opportunity to meet and connect with one another they are hoping for programs in the future that addresses topics such as transitioning beyond cancer, dating, self-esteem and fertility and grief and loss. Currently there are few programs that address these issues at cancer camps, cancer clinics or hospitals.

This brings to light the second key finding from this research which was that there is very few programs available to young adult cancer survivors overall. This includes programs at camps, retreats, cancer clinics or hospitals. In fact, some of the only places these programs exist for young adult cancer survivors are at cancer camps. This can truly be measured in the fact that there are 76 camps for pediatric cancer survivors and only six camps or retreats for young adult cancer survivors. This is shocking considering that pediatric cancer survivors make up only 1% of the total cancer population and young adults make up five times that amount nationally. Improving the quality of life for these young survivors through effective programming is

important. Decreasing stress and enhancing coping strategies for young adult survivors during the adjustment of such a non-normative life event is important. The stressors are overwhelming for young adult survivors and social support programming has shown conclusively to help these young survivors in a myriad of ways.

Implications

Young adult cancer survivors come up against what seem to be insurmountable odds. They suffer four-fold from a lack of research, resources, more intense psychological issues and more progressed stages of cancer once diagnosed. In addition to diagnosis they are typically in treatment for one to two years. Moreover YACS are often in treatment longer than other age groups, due to the fact they are being diagnosed at more progressed stages of cancer. This is due to the fact YACS have limited access to health insurance, which results in fewer doctor visits, and once seen by a doctor their physical symptoms are often misdiagnosed (Rosenthal, 2009, p. 3).

Due to later stages of diagnosis, cancer treatment for YACS is often more aggressive and typically involves the combination of chemotherapy, surgery and radiation for a period of one to two years (Soliman, 2008, p. 56). This is longer than typically experienced by pediatric and geriatric survivors, who are typically diagnosed in earlier stages and have better survival rates overall (Hobson, 2007, p. 76). In addition to being diagnosed at later stages of cancer this age group typically suffers from more intense psychological issues than other cancer populations.

It is not surprising that a later stage of diagnosis for a young adult cancer survivor, which results in long-term aggressive cancer treatment, would affect mental, emotional and cognitive functioning. This in turn effects the young adult's perception of stressors and coping skills (Evan, 2006, p. 1667). The psychological issues that affect this age demographic include

adjustment problems, somatic complaints, concerns about health, hyper-vigilance, anxiety over recurrence, life stressors, and academic difficulties (Zelter, 1993, p. 3466). Accompanying this, some studies have noted that more advanced stages of treatment are associated with more severe PTSD symptoms (Kangas, 2002, p. 510).

This research conclusively shows that peer support programs effectively benefit young adult cancer survivors' quality of life. Peer support helps survivors with coping strategies, reduces anxiety and depression and helps with psychosocial rehabilitation (Epping-Jordan, 1994, p. 546). In 1998, the American Cancer Society Task Force on Children and Cancer reported that "The progress achieved in attaining 80% survival among children and adolescents and young adults with cancer can be justified ONLY if their physical, emotional, and social quality of life also are protected" (Haase, Maure, & Reaman, 1998, p. 822).

It is clear from this research that hospitals and cancer clinics have failed to provide the emotional and social support that is fundamentally necessary for a better quality of life for young adult cancer survivors. Even the most basic of programming, such as cancer survivor support groups, are a rare offering for this population. This can be seen in a survey of 217 young adult survivors that indicates: 75% had a need for more peer support programs; 95% wanted internet sites that were geared toward young adults; and 62% wanted programs, such as camp or workshops that offer education and support (Zebrack, 2009, p. 352-4).

In addition, for physicians to be able to recommend these programs they first need to exist. Studies show that one in four cancer survivors participate in support groups, and 78% of participants benefit, yet groups are only recommended by physicians 10% of the time (Owen, 2007, p. 2586; Holland, 2005, p. 2625). Moreover, cancer camps should not be held responsible for providing supplemental programming that healthcare settings do not. Currently, however,

this is the role that these cancer camps are playing. Key programs that camps do currently provide address emotional support, coping strategies and connections to resources.

Recommendations

What is important to consider is how these programs are not being offered at cancer clinics or hospitals for young adult cancer survivors. These programs are paramount within a clinical setting due to the extensive and aggressive treatment that young adults endure. Overall, there is a great need for more programs of ALL TYPES for young adult cancer survivors. Art can be used within these programs to help facilitate a more open, interactive, participatory experience as young adults bond with their peers and process their cancer journey together. Art can also be used for constructing art objects, such as a photojournals. These objects can be used as take-aways that help trigger happy memories or assist in the processing of one's cancer experience.

A majority of these programs for young adult cancer survivors can only be found within cancer survivor camps. I highly recommend that these programs be incorporated into cancer clinics and hospitals, especially within healthcare facilities that serve a large number of this population. Young adults have unique needs when coping with cancers that are different from older adults and children.

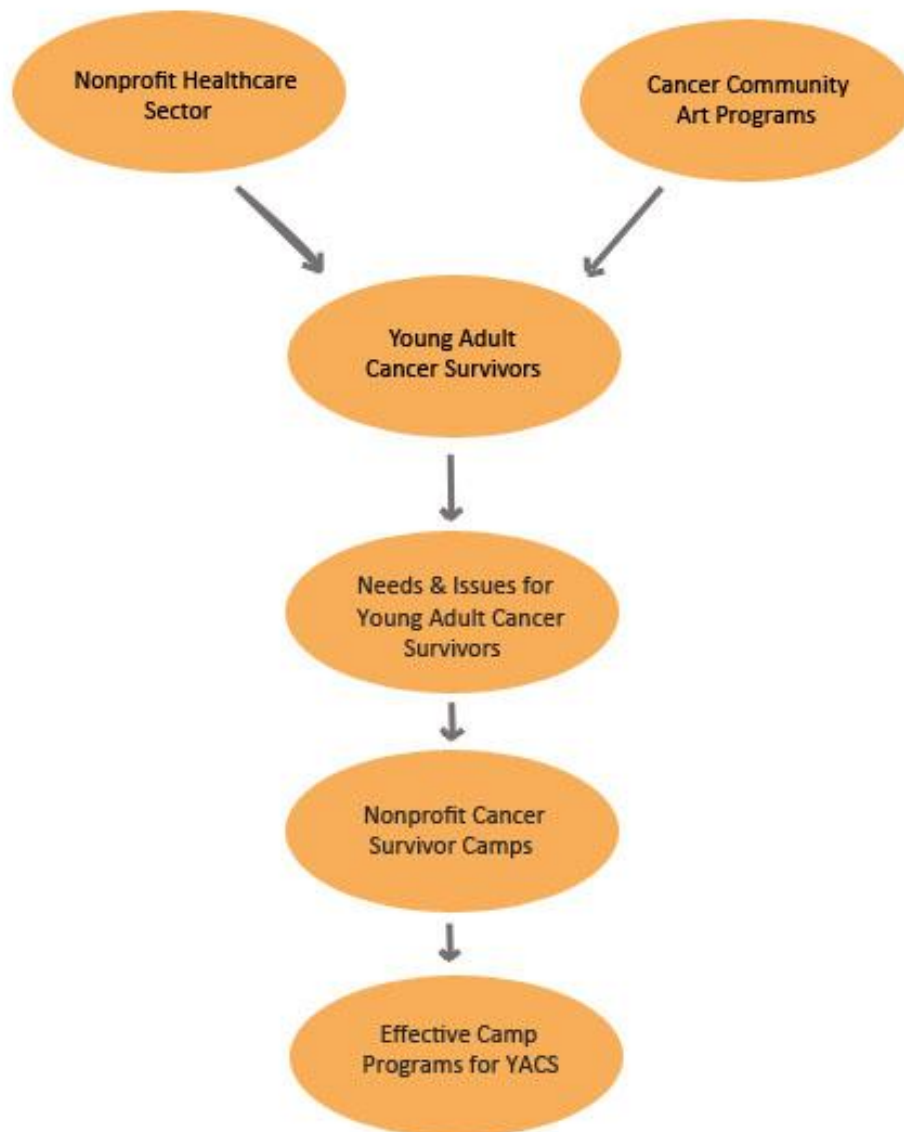
In closing, it is also important that further research on the effectiveness of peer support interventions and other psychological interventions for young adult cancer survivors be explored. Research designed to enhance well-being in cancer patients and survivors is still in its infancy (Stein, 2008, p.2587). In addition, the YAC population is understudied overall. This field will benefit from future research on the influence of peer support on adjustment and coping of young adult cancer survivors (Evan, 2006; Love, 2011; Soliman, 2008; Zebrack, 2006).

This research is important in guiding practitioners and program developers as they establish supportive cancer care programs for young adults in the future. Improving the quality of life for these young survivors through effective programming is important. The stressors are overwhelming for young survivors and social support programs have shown conclusively to help these young survivors in many ways.

Appendices

Appendix A: Conceptual Framework Schematic

Conceptual Framework Schematic



Appendix B: Research Timeline

Master's Research Timeline - 2011-2012

Spring 2011

AAd 604

- Continue literature review
- Consult with research advisor, Hager
- Consult with arts and healthcare advisor, Dewey

Summer 2011

- Reflective Journaling as Program Facilitator about campers program engagement at young adult cancer camp session.

Fall 2011

AAd 631

Submit Human Subjects Application

- Draft human subjects documents
- Create and finalize human subjects documents
- Complete CITI training
- Complete full research proposal
- Meet regularly with research and healthcare advisor – Hager & Dewey
- Draft detailed research instruments

Winter 2012

AAd 503 or 601

- Convert proposal into chapter drafts
- Plan when chapters will be due with advisor
- Meet regularly with research advisor – now Patricia Dewey
- Refine research instruments by OPHS requirements
- Schedule Data Collection: recruit for interviews of camp staff

By February:

- Begin Data Collection and analysis
- Analyze the data collected over the summer –reflective observations as facilitator
- Begin submitting chapter drafts for feedback

Spring 2012

AAd 503 or 601

- Begin bringing together the components of the final full document
- Complete Data Collection – interviews, online survey, observations summarized
- Analyze data
- Write full first draft of final document – continue to submit chapters to advisor for review and feedback

By May:

- Meet deadline for draft of full document submitted to advisor -4/30/12
- Receive feedback about full draft document
- Present master's research – 5/18/12
- Deadline to submit text and images for inclusion into research journal – 4/30/12
- Continue to revise full document
- Deadline for full final draft submitted to advisor – 6/01/12

By June:

- Final Document Due (3 copies) and PDF – 6/12/12

Appendix C: Research Instruments

Research Instruments

Through document analysis of cancer survivor camp studies it is significant to note that these camps are effective in decreasing stress and enhancing coping strategies. However, all of the studies acknowledge a lack of knowledge regarding efficacy of camp programs, specifically in regard to descriptive assessments designed to better understand the engagement and perspective of participants.

The qualitative methods of data analysis I would like to use in this research includes data that I collected in my work as a program facilitator for a nonprofit cancer camp in the summer of 2011. As a part of my work as a program facilitator I observed campers participating in programming and graphed program efficacy (delineated by the number of campers engaged in each program). I also reflectively journaled about campers' participation and about my experience as a program facilitator at the camp. This data was collected for non-research purposes, as a part of my role as a program facilitator. I am now proposing to use this data, which I collected as a program facilitator, for my research.

In addition to the data previously collected as a program facilitator at a cancer survivor camp, I also want to collect data through transcribed informal, candid interviews with administrators of the camp. Along with the document analysis and journaled observations as a program facilitator at the case-study site, the informational interviews of camp staffers, who are key informants within that culture, will inform this research strategy.

In addition to the interviews of camp administrators, an online survey of this population will be collected to gain the camp participants perspective of programming at cancer camps. So that all human subjects remain anonymous the online survey provider Survey Monkey will be used.

Research Instruments:

- Document Analysis
- Reflective Journal Entries of program participants collected as a program facilitator
- Informational Interviews of administrators of cancer survivor camps
- An Online Survey of participants' perspective of effectiveness and engagement of programs at camp.

Appendices D: Research Clearance for Master's Project

04/26/2012 THU 9:42 FAX 541 346 6224

001/001

University of Oregon



Graduate School
(541) 346-5129

RESEARCH CLEARANCE FOR MASTER'S THESIS/PROJECT OR DOCTORAL DISSERTATION

FILL IN THIS FORM ON-SCREEN. HANDWRITTEN FORMS WILL NOT BE ACCEPTED.

Student Name: Saunders Last Emily First A M.I.
Address: 260 West 6th Ave Apt #9 Street Eugene City OR 97401 State Zip Code
Student Number: 951-00-9555 E-Mail: saunder2@uoregon.edu
Major: Arts Management Department: Arts and Administration

The research clearance form is required to be completed, signed, and on file in the Graduate School, even if your work does not require human or animal subjects. Failure to follow required procedures may result in a recommendation to the Dean of the Graduate that the university not accept your thesis/project, or dissertation.

Requesting clearance for: Master's Thesis Master's Project Doctoral Dissertation

Title of thesis/project or dissertation: Cancer Survivor Camps: Programming for Young Adult Cancer Survivors

Title of human subjects project, if different: same

Student Signature: _____ Date: _____

FACULTY ENDORSEMENT OF RESEARCH

This is to certify that the department approves the research project as identified above.

Patricia Dewey Arts and Administration 4/18/2012
Advisor Name Department Signature Date
Doug Blandy Arts and Administration 4/18/2012
Department Head Department Signature Date

ANIMAL SUBJECTS RESEARCH

Yes No This thesis/project or dissertation involves animal subjects research.

If yes, obtain approval of the research protocol from the Institution Animal Care and Use Committee (IACUC) before purchasing or using animals.

Protocol #: _____ Approval Date: _____

Verification of IACUC Approval: _____
IACUC Office Signature Date

HUMAN SUBJECTS RESEARCH

Yes No This thesis/project or dissertation involves human subjects research.

If yes, obtain approval of the research protocol from the Committee for the Protection of Human Subjects (CPHS) before collecting data.

Protocol #: 01302012.038 Approval Date: 4/5/12

Verification of CPHS Approval: _____
Office for Protection of Human Subjects Signature Date

GRADUATE SCHOOL APPROVAL

Approved Disapproved

S. Morgan 4/27/12
Signature of the Dean or Associate Dean of the Graduate School Date

Appendices E: Recruitment Letter for Interview with Camp Administrators

Dear Camp Administrator,

My name is Emily Saunders and I am a Graduate Student from the Arts and Administration Department at the University of Oregon. I am writing to invite you to participate in my research study about the benefits of cancer survivor camps for young adults. You're eligible to be in this study because you are an administrator of a cancer survivor camp with programs for young adult cancer survivors/patients. I obtained your contact information from working at camp as a program facilitator the summer of 2011.

If you decide to participate in this study, you will be informally interviewed for information about the benefits of camp programs for young adult cancer survivors. I would like to audio record your interview and then use the information to build on the research about the effectiveness of cancer survivor camps for young adults.

Remember, this is completely voluntary. You can choose to be in the study or not. If you'd like to participate or have any questions about the study, please email or contact me at saunder2@uoregon.edu or 503-267-0392.

Thank you very much.

Sincerely,

Emily Saunders

Appendix F: Interview Consent Form

University of Oregon Consent Form
University of Oregon Arts and Administration Department
Informed Consent for Participation as a Subject in Cancer Survivor Camps
Investigator: Emily Saunders
Type of consent: Adult Consent Form

Introduction

- You are being asked to be in a research study of the benefits of cancer survivor camps for young adult cancer survivors.
- You were selected as a possible participant because you are a cancer camp administrator.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study:

- The purpose of this study is: To determine what the benefits are of cancer survivor camps for young adults. I am researching what camp programs are effective. What art programming at camp is effective. And in what ways these camps improve the quality of life for young adult camp participants. There exists a lack of knowledge regarding the effectiveness of camp programs and this study helps bridge that lack of knowledge.
- Participants in this study are from the Administrative Staff of cancer survivor camps.

Description of the Study Procedures:

- If you agree to be in this study, we would ask you to do the following things: Participate in an informal, candid informational interview about cancer camp programs for no longer than one hour.

Risks/Discomforts of Being in the Study:

- There are no reasonable foreseeable (or expected) risks to participating in an informal, informational interview about cancer survivor camp programming by camp administrators.
- This study may include risks that are unknown at this time.

Benefits of Being in the Study:

- The purpose of the study is to determine what the benefits are of cancer survivor camps for young adults.
- There are no expected benefits for participating in this informal, informational interview.

Payments:

- There will be no payments or reimbursement for participating in this interview.

Costs:

- There is no cost to you to participate in this research study.

Confidentiality:

- The records of this study will be kept private. In any sort of report we may publish, we will not include any information that will make it possible to identify a participant. Research records will be kept in a locked file.
- All electronic information will be coded and secured using a password protected file. Audio recordings of the interview will only be accessed by me, the researcher. These audio recordings will be erased/destroyed on July 1st 2012 by deleting the audio recordings.
- Access to the records will be limited to the researcher.

Voluntary Participation/Withdrawal:

- Your participation is voluntary. If you choose not to participate, it will not affect your current or future relations with the University.
 - You are free to withdraw at any time, for whatever reason.
 - There is no penalty or loss of benefits for not taking part or for stopping your participation.
- *You will be provided with any significant new findings that develop during the course of the research that may make you decide that you want to stop participating.

Contacts and Questions:

- The researcher conducting this study is Emily Saunders. For questions or more information concerning this research you may contact her/him/them at 503-267-0392 or saunder2@uoregon.edu .
- If you believe you may have suffered a research related injury, contact Emily Saunders at 503-267-0392 who will give you further instructions.
- If you have any questions about your rights as a research subject, you may contact: the Office for Protection of Human Subjects, University of Oregon at (541-346-2510) or human_subjects@uoregon.edu

Copy of Consent Form:

- You will be given a copy of this form to keep for your records and future reference.

Statement of Consent:

- For Adult Consent Form combined Consent/Assent: I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to participate in this study. I have received (or will receive) a copy of this form.

Signatures/Dates**Study Participant (Print Name):**

Participant or Legal Representative Signature :
Date:

Appendix G: Interview Questions for Camp Administrators

Camp Administrator Interview Questions:

What is your title at camp?

How long have you been working as an administrator at a cancer survivor camp?

What camp programs are typically offered at camp for young adult cancer survivors?

What camp programs have you found young adult participants to be most engaged in? Which of these programs do you feel have been most effective for young adult participants?

Specifically, why do you feel these programs were more effective? What made these programs more effective than others offered?

What is the goal or mission of the camp's programs for young adult cancer survivors?

What are the benefits of cancer survivor camps for young adult cancer survivors?

What art programming did you feel was the most effective and engaging at camp for young adult participants?

What programs for young adult participants would you like to provide in the future at cancer survivor camps, if there were no limitations to what you could do?

Appendices H: List of Participants Interviewed

Beth Jones, Camp Director
Camp Mak-A-Dream, Gold Creek Montana
Interview Date: May 9th 2012
Interview by telephone: 10am-11am

Tonia Farman, Founder & Director
Athletes for Cancer Camp, Maui
Interview Date: May 9th 2012
Interview by telephone: 1pm-2pm

Meg Keigley, Program Director
Camp Mak-A-Dream, Gold Creek, Montana
Interview Date: May 15th 2012
Interview by telephone: 12pm-12:30pm

Appendices I: Recruitment Letter & Consent Form for Online Survey

Dear Prospective Participant,

My name is Emily Saunders. I am a Graduate Student in the Arts and Administration Program from the University of Oregon. I am conducting an anonymous survey about cancer camp programs for young adult cancer camp participants. These camps are effective in decreasing stress and enhancing coping strategies. However, there is a lack of knowledge about the effectiveness of these camp programs for young adults. There is very little information available about the perspective of the camp participants when it comes to engaging in these camp programs. This survey gathers your perspective about camp programs.

To participate, you must be 18 years or older. The survey is voluntary. Completing the survey serves as the informed consent form for participating in the survey.

Last summer, at Camp Mak-A-Dream, I worked as a program facilitator. As a young adult cancer survivor, myself, I was motivated to study what social support and programming is beneficial for young adult cancer survivors. As a part of my work as a program facilitator I observed campers' participating in programming and charted program efficacy (charted as the number of campers engaged in each program) from June 15th to June 22nd, 2011.

No names were recorded as a part of my observation process as a facilitator at camp. All participants are anonymous. This data was collected for non-research purposes, as a part of my role as a program facilitator. I am now using this data, which I collected as a program facilitator, for my research about cancer survivor camp's programming.

Since your answers for this survey are to remain anonymous, PLEASE DO NOT PUT YOUR NAME ON THIS SURVEY.

The survey will take 15 minutes. Please answer the questions to your comfort level.

The results will be reported for the group of respondents as a whole.

Thank you for your consideration.

This survey will be available online from April 30th – May 7th 2012.

Sincerely,

Emily Saunders
saunder2@uoregon.edu
503-267-0392

Appendices J: Survey Questions

1. What was your reason for attending a cancer camp for young adult cancer survivors?

- To meet and connect with other young adult cancer survivors
- To participate in specific programs
- To learn coping strategies from other young adult cancer survivors
- To connect with resources for young adult cancer survivors
- For emotional support
- For a vacation
- Other (please specify)

2. As a young adult cancer survivor camp participant, what programs have you found to be the most effective and engaging at a cancer camp?

- Recreational Activities: Zip line, Surfing, High Ropes Course, Snowboarding, Horseback Riding, ect.
- Art Programming: Photo-journaling, Movie-Making, Arts & Crafts, Tile Painting, ect.
- Educational Workshops covering: Medical Issues, Intimacy or Fertility Concerns, Counseling/Support Group Resources, Excercise & Nutrition, ect.
- Social Interactions: Evening Campfire Discussions and Cabin Discussions
- Other (please specify)

3. Why did you find this specific program to be the most engaging?

- The social interaction with other young adult survivors
- Being able to try a new recreational activity
- Obtaining knowledge about relevant issues
- Being able to be creative
- Other (please specify)

4. Within these programs at camp what topics (or subject matter) did you really appreciate being able to discuss?

- Each other's personal survivorship story
- Issues of transitioning after cancer treatment ended
- Self-esteem and body issues
- Dating and relationship concerns
- Fertility concerns & intimacy concerns
- Coping strategies/emotional support/help with distress
- Grief and loss
- Other (please specify)

5. Specifically how have you benefited from attending and participating in cancer camp programming?

- Connecting with other young adult cancer survivors
- Learning and participating in a new activity
- Gaining new information on relevant issues
- Learning new coping strategies
- Other (please specify)

6. In the future, what programs for young adult cancer survivors would you like to see at cancer camps?

- Programs that have more talking / interaction with other young adult survivors
- Programs with more recreational activities
- Programs with more emotional support & counseling
- Programs that connected you to more resources outside of camp
- Other (please specify)

7. In the future, within these programs at camp what topics (or subject matter) would you really appreciate being discussed?

- Each other's personal survivorship story
- Transitioning issues after cancer treatment
- Self-esteem, body issues
- Dating and relationship concerns
- Fertility concerns & intimacy concerns
- Coping strategies/emotional support/help with distress
- Grief and loss
- Other (please specify)

8. The last two questions are about art programming at camp. What art programming at camp did you find the most engaging?

- Photo-journaling
- Arts & Crafts
- Movie-Making
- Painting tiles, t-shirts or wooden plaques
- Other (please specify)

9. Why did you find this art program to be the most engaging?

- The project helped me reflect on my cancer journey
- I was able to create an object to remember camp
- Creative interaction time with other young adult survivors
- It helped me document my time at camp to reflect on later

Appendices K: Results from Online Survey

What was your reason for attending a cancer camp for young adult cancer survivors?

To meet and connect with other young adult cancer survivors	95%	19
To participate in specific programs	15%	3
To learn coping strategies from other young adult cancer survivors	35%	7
To connect with resources for young adult cancer survivors	35%	7
For emotional support	50%	10
For a vacation	55%	11

As a young adult cancer survivor camp participant, what programs have you found to be the most effective and engaging at a cancer camp?

Recreational Activities: Zip line, Surfing, High Ropes Course, Snowboarding, Horseback Riding, ect.	70%	14
Art Programming: Photo-journaling, Movie-making, Arts & Crafts, Tile Painting, ect.	45%	9
Educational Workshops covering: Medical issues, Intimacy or Fertility Concerns, Counseling/Support Group Resources, Excercise & Nutrition, ect	45%	9
Social Interaction: Evening Campfire Discussions and Cabin Discussions	95%	19

Why did you find this specific program to be the most engaging?

The social interaction with other young adult survivors	85%	17
Being able to try a new recreational activity	25%	5
Obtaining knowledge about relevant issues	15%	3
Being able to be creative	30%	6

Within these programs at camp what topics (or subject matter) did you really appreciate being able to discuss?

Each other's personal survivorship story	57.9%	11
Issues of transitioning after cancer treatment ended	15.8%	3
Self-esteem and body issues	0%	0
Dating and relationship concerns	0%	0
Fertility concerns & intimacy concerns	0%	0
Coping strategies/emotional support/help with distress	15.8%	3
Grief and loss	10.5%	2

Specifically how have you benefited from attending and participating in cancer camp programming?

Connecting with other young adult cancer survivors	95%	19
Learning and participating in a new activity	30%	6
Gaining new information on relevant issues	25%	5
Learning new coping strategies	35%	7

In the future, what programs for young adult cancer survivors would you like to see at cancer camp?

Programs that have more talking/ interaction with other young adult survivors	63.2%	12
Programs with more recreational activities	31.6%	6
Programs with more emotional support & counseling	31.6%	6
Programs that connected you to more resources outside of camp	31.6%	6

In the future, within these programs at camp what topics (or subject matter) would you really appreciate being discussed?

Each other's personal survivorship story	61.1%	11
Transitioning issues after cancer treatment	55.6%	10
Self-esteem, body issues	38.9%	7
Dating and relationship concerns	22.2%	4
Fertility concerns & intimacy concerns	22.2%	4
Coping strategies/emotional support/help with distress	50%	9
Grief and loss	22.2%	4

The last two questions are about art programming at camp. What art programming at camp did you find the most engaging?

Photo-journaling	29.4%	5
Arts & Crafts	52.9%	9
Movie-making	11.8%	2
Painting tiles, t-shirts or wooden plaques	52.9%	9

Why did you find this art program to be the most engaging?

Creative interaction time with other young adult survivors	52.9%	9
The project helped me reflect on my cancer journey	52.9%	9
I was able to create an object to remember camp	58.8%	10
It helped me document my time at camp to reflect on later	47.1%	8

Appendices L: Chart of Camp Program Participation by Young Adults

Young Adult Camp Session at Camp Mak-A-Dream: June 15th – 22nd 2011

35 Campers Total

Attendance of Sessions – All programs are voluntarily attended

Introduction to Camp / Ice Breaker	100%
Cabin Chat – daily confidential camper conversations in each cabin	80%
Art Session – Image Transfer Express Yourself on a t-shirt creative session	75%
Arts & Crafts free time in Art Barn - offered nightly	50%
Imerman Angel – lecture and resource for connecting young adult survivors	95%
Meditation & Yoga Session	50%
Horseback Riding	15%
Directions in Health & Wellness: fitness and nutrition workshop	25%
Medical Education Session	80%
Photojournal Sessions - 3 in total	60%
Evening Fun Activity: Halloween, Bake-off,	75%
Movie about cancer journey for young adult cancer survivors	95%
Banquet Dinner	100%
Karaoke Dance Party	75%
Day Trip to Philisburg: Mining & Silk Scarf Painting	100%
Talent Show / Closing Ceremony / Awards Ceremony / Slide Show	100%
Drum Circle	95%
Day Trip to Missoula Farmers Market / Craft Market	95%
High Ropes Course	85%
Look Good, Feel Better Session	25%

References

- Adams, P. (January 01, 1998). When healing is more than simply clowning around. *Jama : the Journal of the American Medical Association*, 279, 5.)
- Anagnos, V. (December 07, 2004). New Survey Indicates More Than Half of US Hospitals Have Arts Programs. *Goodman Media International*, Retrieved from www.americansforthearts.org
- Americans for the Arts. (March 14, 2011). Arts & Healthcare: Strengthening our Nation's Healthcare Through the Arts. *Arts and Healthcare action to Congress*, Retrieved from www.americansforthearts.org
- Baker, F., Denniston, M., Smith, T., & West, M. M. (January 01, 2005). Adult cancer survivors: how are they faring?. *Cancer*, 104, 11, 2565-76.
- Baker, F., Liberatos, P., Denniston, M., & Haffer, S. C. (July 01, 2009). Change in health-related quality of life of newly diagnosed cancer patients, cancer survivors, and controls. *Cancer*, 115, 13, 3024-3033.
- Balen, R. (December 01, 1996). Activity Camps for Children with Cancer. Research Review. *Children & Society*, 10, 4, 317-23.
- Bamberger, M., Rugh, J., Church, M., & Fort, L. (January 01, 2004). Shoestring Evaluation: Designing Impact Evaluations under Budget, Time and Data Constraints. *American Journal of Evaluation*, 25, 1, 5-37
- Barnett, L. A. (1988). *Research about leisure: Past, present and future*. Champaign, IL: Sagamore Pub
- Bar-Sela, G., Atid, L., Danos, S., Gabay, N., & Epelbaum, R. (January 01, 2007). Art therapy improved depression and influenced fatigue levels in cancer patients on chemotherapy. *Psycho-oncology*, 16, 11, 980-4.
- Baum, A., & Andersen, B. L. (2001). *Psychosocial interventions for cancer*. Washington, D.C: American Psychological Association.
- Ben-Aryeh, A. (2001). *Measuring and monitoring children's well-being*. Dordrecht: Kluwer Academic Publishers
- Bleyer, W. A. (January 01, 2002). Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Medical and Pediatric Oncology*, 38, 1, 1-10.
- Bleyer, A. (January 01, 2007). Young adult oncology: the patients and their survival challenges. *Ca: a Cancer Journal for Clinicians*, 57, 4, 242-55.

- Bluebond-Langner, M., Perkel, D., Goertzel, T., Nelson, K., & McGeary, J. (January 01, 1990). Children's knowledge of cancer and its treatment: impact of an oncology camp experience. *The Journal of Pediatrics*, 116, 2, 207-13.
- Borrupt, T., Partners for Livable Communities., & McKnight Foundation. (2006). *The creative community builder's handbook: How to transform communities using local assets, art, and culture*. Saint Paul, Minn: Fieldstone Alliance.
- Bottomley, A., & Jones, L. (January 01, 1997). Social support and the cancer patient--a need for clarity. *European Journal of Cancer Care*, 6, 1, 72-7.
- Bracken, J. (2010). *Children with Cancer: A comprehensive reference guide for parents*. New York: Oxford University Press.
- Briery, B. G., & Rabian, B. (January 01, 1999). Psychosocial changes associated with participation in a pediatric summer camp. *Journal of Pediatric Psychology*, 24, 2, 183-90.
- Cairns, N. U., Clark, G. M., Smith, S. D., & Lansky, S. B. (January 01, 1979). Adaptation of siblings to childhood malignancy. *The Journal of Pediatrics*, 95, 3, 484-7.
- Carboon, I., Anderson, A., Pollard, A., Szer, J., Seymour J. (December, 2005) Posttraumatic Growth Following a Cancer Diagnosis: Do World Assumptions Contribute? *Traumatology 11*: 269-283.
- Cassileth, B. R., Lusk, E. J., Miller, D. S., Brown, L. L., & Miller, C. (January 01, 1985). Psychosocial correlates of survival in advanced malignant disease?. *The New England Journal of Medicine*, 312, 24, 1551-5.
- Cella, D. F., & Tross, S. (January 01, 1986). Psychological adjustment to survival from Hodgkin's disease. *Journal of Consulting and Clinical Psychology*, 54, 5, 616-22.
- Chung, J. Y. Y., & University of Guelph. School of Graduate Studies. Dept. of Psychology., (1999). *Siblings of children with cancer: Opening the opportunities for participation*.
- Cordova, M. J., Andrykowski, M. A., Kenady, D. E., McGrath, P. C., Sloan, D. A., & Redd, W. H. (January 01, 1995). Frequency and correlates of posttraumatic-stress-disorder-like symptoms after treatment for breast cancer. *Journal of Consulting and Clinical Psychology*, 63, 6, 981-6.
- Cruze, P. D. (January 01, 1998). Healing cast in a new light: the therapy of artistic creation. *Jama : the Journal of the American Medical Association*, 279, 5.)
- Davidson, E. J. (2005). *Evaluation methodology basics: The nuts and bolts of sound evaluation*. Thousand Oaks, Calif: Sage Publications.

- Decker, C. L. (January 01, 2007). Social support and adolescent cancer survivors: A review of the literature. *Psycho-oncology*, *16*, 1, 1-11.
- Deimling, G. T., Kahana, B., Bowman, K. F., & Schaefer, M. L. (January 01, 2002). Cancer survivorship and psychological distress in later life. *Psycho-oncology*, *11*, 6.
- Elad, P., Yagil, Y., Cohen, L., & Meller, I. (January 01, 2003). A jeep trip with young adult cancer survivors: lessons to be learned. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *11*, 4, 201-6.
- Epping-Jordan, J. E., Compas, B. E., & Howell, D. C. (January 01, 1994). Predictors of cancer progression in young adult men and women: avoidance, intrusive thoughts, and psychological symptoms. *Health Psychology : Official Journal of the Division of Health Psychology, American Psychological Association*, *13*, 6, 539-47.
- Epstein, I., Stinson, J., & Stevens, B. (January 01, 2005). The effects of camp on health-related quality of life in children with chronic illnesses: a review of the literature. *Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses*, *22*, 2, 89-103.
- Evan, E. E., Kaufman, M., Cook, A. B., & Zeltzer, L. K. (January 01, 2006). Sexual health and self-esteem in adolescents and young adults with cancer. *Cancer*, *107*, 7, 1672-9.
- Evan, E. E., & Zeltzer, L. K. (January 01, 2006). Psychosocial dimensions of cancer in adolescents and young adults. *Cancer*, *107*, 7, 1663-71.
- Fisher, C., Lerner, R., (2005). *Encyclopedia of applied developmental science, Vol 2*. Sage Publications Inc..
- Gilbert, G. N. (1993). *Researching social life*. London: Sage.
- Haase, G. M., Mauer, A. M., & Reaman, G. H. (January 01, 1998). Survivorship in childhood cancer: a case statement for enhancement of the role of the American Cancer Society. Task Force on Children and Cancer of the American Cancer Society. *Cancer*, *83*, 4, 821-3.
- Haase, J. E., & Phillips, C. R. (May 01, 2004). The Adolescent/Young Adult Experience. *Journal of Pediatric Oncology Nursing*, *21*, 3, 145-149.
- Hathorn, K., & Nanda, U. (2008). A Guide to Evidence-Based Art. *The Center for Health Design*, 1-22. Retrieved from http://archived.healthdesign.org/advocacy/adgroups/documents/Hathorn_Nanda_Mar08_001.pdf

- Heaphy, A., & Bansal, A. (November, 2008). Arts in Healthcare: Best Practices. *National Endowment for the Arts*. Retrieved from www.nea.gov/resources/accessibility/Arts-and-Healthcare-Best-Practices.pdf
- Heiney, S. P., & Darr-Hope, H. (January 01, 1999). Healing Icons: art support program for patients with cancer. *Cancer Practice*, 7, 4, 183-89.
- Hensley, A. L. (2009c). Betrayal trauma: Insidious purveyor of PTSD. In G. Dougherty (Ed.). *Return to equilibrium: Proceedings of the 7th Rocky Mountain Region Disaster Mental Health Conference* (pp. 105-148). Ann Arbor, MI: Loving Healing Press.
- Hobson, K. (January 15, 2007). Cancer's Orphan Generation. *U.s. News & World Report*, 142, 2, 76-77.
- Holland, J. C., & Reznik, I. (January 01, 2005). Pathways for psychosocial care of cancer survivors. *Cancer*, 104, 11, 2624-37.
- Hume, V. (January 01, 2010). Creative care: the role of the arts in hospital. *Nursing Management (harrow, London, England : 1994)*, 17, 5, 16-20.
- Hvizdala, E. V., Miale, T. D., & Barnard, P. J. (January 01, 1978). A summer camp for children with cancer. *Medical and Pediatric Oncology*, 4, 1, 71-5
- Jamison, R. N., Burish, T. G., & Wallston, K. A. (January 01, 1987). Psychogenic factors in predicting survival of breast cancer patients. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 5, 5, 768-72.
- Jones, B. L., Barczyk, A., & Parker-Raley, J. (August 01, 2011). Adolescent cancer survivors: Identity paradox and the need to belong. *Qualitative Health Research*, 21, 8, 1033-1040.
- Kangas, M., Henry, J. L., & Bryant, R. A. (May 01, 2002). Posttraumatic stress disorder following cancer: A conceptual and empirical review. *Clinical Psychology Review*, 22, 4.
- Katz, E. (1980). Illness Impact and Social Reintegration. In J. Kellerman (Ed.), *Psychological Aspects of Childhood Cancer*. Springfield, IL: Charles C. Thomas.
- Kessell, M., Resnick, M. D., & Blum, R. W. (January 01, 1985). Adventure, Etc.--a health-promotion program for chronically ill and disabled youth. *Journal of Adolescent Health Care : Official Publication of the Society for Adolescent Medicine*, 6, 6, 433-8.
- Koocher, G. P., & O'Malley, J. E. (1981). *The Damocles syndrome: Psychosocial consequences of surviving childhood cancer*. New York: McGraw-Hill.

- Lane, M. R. (January 01, 2006). Arts in health care: a new paradigm for holistic nursing practice. *Journal of Holistic Nursing : Official Journal of the American Holistic Nurses' Association*, 24, 1, 70-5.
- Love, C., & Sabiston, C. M. (January 01, 2011). Exploring the links between physical activity and posttraumatic growth in young adult cancer survivors. *Psycho-oncology*, 20, 3, 278-86.
- Martiniuk, A. L. (January 01, 2003). Camping programs for children with cancer and their families. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, 11, 12, 749-57.
- McCarthy, P. G., & Sebaugh, J. G. (March 01, 2011). Therapeutic scrapbooking: A technique to promote positive coping and emotional strength in parents of pediatric oncology patients. *Journal of Psychosocial Oncology*, 29, 2, 215-230.
- McDavid, J. C., & Hawthorn, L. R. L. (2006). *Program evaluation & performance measurement: An introduction to practice*. Thousand Oaks: SAGE Publications.
- McGoldrick, D., Neal, C., & Whiteson, M. (May 01, 2008). Advocacy and adolescent/young adult cancer survivors. *Pediatric Blood and Cancer*, 50, 1109-1111.
- Mehnert, A., & Koch, U. (January 01, 2007). Prevalence of acute and post-traumatic stress disorder and comorbid mental disorders in breast cancer patients during primary cancer care: a prospective study. *Psycho-oncology*, 16, 3, 181-8.
- Meltzer, L. J., & Rourke, M. T. (January 01, 2005). Oncology Summer Camp: Benefits of Social Comparison. *Children's Health Care*, 34, 4, 305-314.
- Montanaro, R. (2007). *Creative Arts Therapy Programs for Pediatric Oncology Patients: A comparative case study*. Eugene: University of Oregon Press.
- Nainis, N., Paice, J. A., Ratner, J., Wirth, J. H., Lai, J., & Shott, S. (February 01, 2006). Relieving Symptoms in Cancer: Innovative Use of Art Therapy. *Journal of Pain and Symptom Management*, 31, 2, 162-169.
- Owen, J. E., Goldstein, M. S., Lee, J. H., Breen, N., & Rowland, J. H. (January 01, 2007). Use of health-related and cancer-specific support groups among adult cancer survivors. *Cancer*, 109, 12, 2580-9.
- Park, C. L., Chmielewski, J., & Blank, T. O. (January 01, 2010). Post-traumatic growth: finding positive meaning in cancer survivorship moderates the impact of intrusive thoughts on adjustment in younger adults. *Psycho-oncology*, 19, 11, 1139-47.

- Pontius, K. (2008). *“We’ve Done Drugs Keith Richard’s Never Heard of”*: A qualitative study of young adult cancer narratives online. Eugene: University of Oregon Press.
- Prior, L. (2003). *Using documents in social research*. London: Sage Publications.
- Rabin, C., Morrow, K., Pinto, B., & Simpson, N. (June 01, 2011). Behavioral and psychosocial program needs of young adult cancer survivors. *Qualitative Health Research*, 21, 6, 796-806.
- Rabin, C., Morrow, K., Pinto, B., & Simpson, N. (June 01, 2011). Behavioral and psychosocial program needs of young adult cancer survivors. *Qualitative Health Research*, 21, 6, 796-806.
- Ridenour, A. (January 01, 1998). Creativity and the arts in health care settings. *Jama : the Journal of the American Medical Association*, 279, 5, 399-400.
- Rosenthal, K. (2009). *Everything changes: The insider's guide to cancer in your 20s and 30s*. Hoboken, N.J: Wiley.
- Schiffman, J. D., Csongradi, E., & Suzuki, L. K. (September 01, 2008). Internet use among Adolescent and Young Adults (AYA) with cancer. *Pediatric Blood and Cancer*, 51, 3, 410-415.
- Schumm, K. (2008). *Art in the Outdoors: Developing a framework to describe residential community-based youth arts camps*. Eugene: University of Oregon Press.
- Shawna, S. (2011). Creativity is Life Force. Retrieved from <http://www.aquidneckacupuncture.com/Art-Therapy.html>
- Singer, S., Gotze, H., Buttstadt, M., Geue, K., Momenghalibaf, A., & Bohler, U. (November 01, 2010). The effects of an art education program on competencies, coping, and well-being in outpatients with cancer – Results of a prospective feasibility study. *The Arts in Psychotherapy*, 37, 5, 363-69.
- Smith, K. E., Gotlieb, S., Gurwitch, R. H., & Blotcky, A. D. (January 01, 1987). Impact of a summer camp experience on daily activity and family interactions among children with cancer. *Journal of Pediatric Psychology*, 12, 4, 533-42.
- Soliman, H., & Agresta, S. V. (January 01, 2008). Current issues in adolescent and young adult cancer survivorship. *Cancer Control*, 15, 1, 55-62.
- Sonke, J., Rollins, J., Brandman, R., & Graham-Pole, J. (September 01, 2009). The state of the arts in healthcare in the United States. *Arts & Health: International Journal for Research, Policy & Practice*, 1, 2, 107-135.

- Stein, K. D., Syrjala, K. L., & Andrykowski, M. A. (June 01, 2008). Physical and psychological long-term and late effects of cancer. *Cancer, 112*, 2577-2592.
- Walsh, S. M., Radcliffe, S., Castillo, L. C., Kumar, A. M., & Broschard, D. M. (January 03, 2007). A Pilot Study to Test the Effects of Art-Making Classes for Family Caregivers of Patients With Cancer. *Oncology Nursing Forum, 34*, 1, E9-E16.
- Wellisch, D. K., Crater, B., Wiley, F. M., Belin, T. R., & Weinstein, K. (January 01, 2006). Psychosocial impacts of a camping experience for children with cancer and their siblings. *Psycho-oncology, 15*, 1, 56-65.
- Winfree, C., Williams, R., & Powell, G. M. (November 01, 2002). Children with Cancer: Positive Benefits of Camp. *Camping Magazine, 75*, 6, 26-33.
- Yi, J., & Zebrack, B. (May 01, 2010). Self-portraits of families with young adult cancer survivors: Using photovoice. *Journal of Psychosocial Oncology, 28*, 3, 219-243.
- Zebrack, B. (January 01, 2008). Information and service needs for young adult cancer patients. *Supportive Care in Cancer, 16*, 12, 1353-1360.
- Zebrack, B. J. (January 01, 2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer, 117*, 10, 2289-94.
- Zebrack, B., Bleyer, A., Albritton, K., Medearis, S., & Tang, J. (January 01, 2006). Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer, 107*, 12, 2915-23.
- Zebrack, B., Oeffinger, K., Hou, P., & Kaplan, S. (January 01, 2006). Advocacy skills training for young adult cancer survivors: the Young Adult Survivors Conference at Camp Mak-a-Dream. *Supportive Care in Cancer, 14*, 7, 779-782.
- Zebrack, B. J., & Zeltzer, L. K. (January 01, 2003). Quality of life issues and cancer survivorship. *Current Problems in Cancer, 27*, 4.
- Zeltzer, L. K. (January 01, 1993). Cancer in adolescents and young adults' psychosocial aspects. Long-term survivors. *Cancer, 71*, 10, 3463-8.