THE IMPACT OF PEER INTERACTION: THE PSYCHOSOCIAL NEEDS AND AVAILABLE SERVICES FOR ADOLESCENT ONCOLOGY PATIENTS

A Project

Presented to the faculty of the Division of Social Work

California State University, Sacramento

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SOCIAL WORK

by

Christine Elise Arneson

SPRING 2013
THE IMPACT OF PEER INTERACTION: THE PSYCHOSOCIAL NEEDS AND AVAILABLE SERVICES FOR ADOLESCENT ONCOLOGY PATIENTS

A Project

by

Christine Elise Arneson

Approved by:

____________________________, Committee Chair
Dr. Francis Yuen, DSW, Professor

____________________________
Date
Student Name: Christine Arneson

I certify that this student has met the requirements for format contained in the University format manual, and that this project is suitable for shelving in the Library, and credit is to be awarded for the project.

__________________________________________, Graduate Coordinator

Dale Russell, Ed.D., LCSW

Division of Social Work
Abstract

of

THE IMPACT OF PEER INTERACTION: THE PSYCHOSOCIAL NEEDS AND AVAILABLE SERVICES FOR ADOLESCENT ONCOLOGY PATIENTS

by

Christine Elise Arneson

This study aims to alleviate the gap in literature regarding the accessibility, utilization, and usefulness of psychosocial interventions for adolescent oncology patients. Specifically, it intends to gain an understanding of the psychosocial services and interventions currently being provided to adolescent oncology patients. Within this, the study intends to compare the perceived usefulness of interventions utilizing interaction between adolescent oncology patients and those that do not. Its primary purpose is to build upon the limited evidence supporting specific strategies for adolescent oncology psychosocial care. In order to do this, a key-informant/experts survey was administered. This research yielded four major findings. First, a high majority of professionals believe peer interaction is important to the psychosocial wellbeing of adolescent oncology patients and a lower percentage perceives their agency feels the same. Second, interventions both with and without peer interaction were identified as useful. However, interventions without peer interaction are more commonly provided internally and
patients are most commonly referred to outside service providers for those providing peer interaction. Rates of perceived utilization of services were much lower than perceived rates of accessibility. Cumulatively, these findings suggest that there is a gap in between the referral and utilization of these services, which are viewed as beneficial to the psychosocial wellbeing of adolescent oncology patients.

_______________________________, Committee Chair
Dr. Francis Yuen, DSW, Professor

_______________________________
Date
ACKNOWLEDGEMENTS

I would like to acknowledge all of my family and friends that supported me throughout my time in graduate school. First, I would like to thank my Mom and Dad for their undying support and love. You have always encouraged me to follow my dreams and inspired confidence in my capabilities to achieve them. The values you instilled in me are what led me into the field of social work. This project, and this graduation would not have been possible without you. I would also like to thank my partner, Matt for his constant support, encouragement, and love. Your positive attitude, selfless acts, and confidence in me made this graduate degree a reality. Additionally, I would like to acknowledge my colleague and dear friend, Annie Temple. Thank you for your abiding compassion, advice, open ears, and authenticity. Graduate school would have been rough without you by my side. I would also like to acknowledge Dr. Yuen and my thesis cohort for their guidance, knowledge, and support throughout the last year. Thank you!
TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Acknowledgments</th>
<th>ii</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Tables</td>
<td>x</td>
</tr>
<tr>
<td>List of Figures</td>
<td>xi</td>
</tr>
</tbody>
</table>

Chapter

1. INTRODUCTION 1

| Background of the Problem | 2 |
| Statement of the Research Problem | 5 |
| Purpose of the Study | 6 |
| Theoretical Framework | 6 |
| Definition of Terms | 8 |
| Assumptions | 9 |
| Justification | 9 |

2. REVIEW OF THE LITERATURE 11

<p>| Psychosocial Needs of Adolescent Cancer Patients | 12 |
| Identity Development | 12 |
| Autonomy | 15 |
| The Psychological and Social Impact of Cancer | 18 |
| Intellectual Needs &amp; Technology Factors | 20 |</p>
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Acceptance and Interpersonal Relationships</td>
<td>22</td>
</tr>
<tr>
<td>Psychosocial Interventions and the Role of Peer Interaction</td>
<td>24</td>
</tr>
<tr>
<td>The Role of Peer Interaction</td>
<td>24</td>
</tr>
<tr>
<td>Psychosocial Intervention Strategies</td>
<td>25</td>
</tr>
<tr>
<td>Evidence-Based Practices and Empirical Data</td>
<td>30</td>
</tr>
<tr>
<td>Utilization and Accessibility of Psychosocial Services</td>
<td>32</td>
</tr>
<tr>
<td>3. METHODOLOGY</td>
<td>33</td>
</tr>
<tr>
<td>Study Design</td>
<td>33</td>
</tr>
<tr>
<td>Sampling Procedures</td>
<td>34</td>
</tr>
<tr>
<td>Data Collection Procedures</td>
<td>35</td>
</tr>
<tr>
<td>Instruments</td>
<td>36</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>37</td>
</tr>
<tr>
<td>Protection of Human Subjects</td>
<td>38</td>
</tr>
<tr>
<td>4. RESULTS</td>
<td>39</td>
</tr>
<tr>
<td>Overall Findings</td>
<td>39</td>
</tr>
<tr>
<td>Respondents and Profession</td>
<td>40</td>
</tr>
<tr>
<td>Respondents and Geographic Location</td>
<td>40</td>
</tr>
<tr>
<td>Distribution of Profession and Location</td>
<td>41</td>
</tr>
<tr>
<td>Specific Findings</td>
<td>43</td>
</tr>
<tr>
<td>Importance of Peer Interaction</td>
<td>44</td>
</tr>
<tr>
<td>Usefulness and Service Provision</td>
<td>45</td>
</tr>
</tbody>
</table>
Interventions with the Most Positive Psychosocial Effects .......... 47

Usefulness, Utilization, and Accessibility ................................. 49

Summary .................................................................................. 51

5. DISCUSSION ............................................................................ 52

Summary of Study ................................................................. 52

Implications for Social Work ................................................... 55

Recommendations ..................................................................... 56

Limitations ................................................................................ 57

Conclusion ................................................................................. 58

Appendix A. Initial Contact Email to Prospective Participants ....... 59

Appendix B. Consent to Participate in Research ......................... 61

Appendix C. Psychosocial Needs and Services for Adolescent Oncology Patients .. 62

Appendix D. Human Subjects Application Approval ................... 67

References ................................................................................ 68
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Tables</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Respondents by Geographic Location</td>
<td>43</td>
</tr>
<tr>
<td>2. Perceived Usefulness of Interventions and Rates of Internal and External Provision</td>
<td>48</td>
</tr>
<tr>
<td>3. Accessibility and Utilization of Interventions</td>
<td>50</td>
</tr>
</tbody>
</table>
## LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figures</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Respondents by Profession</td>
<td>42</td>
</tr>
<tr>
<td>2.</td>
<td>Professionals’ vs. Perceived Agency Ranking of the Importance of Peer</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td>Interaction</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Areas Affected by a Lack of Social or Peer Interaction</td>
<td>46</td>
</tr>
</tbody>
</table>
Chapter 1
INTRODUCTION

The effects of chronic illness permeate nearly every aspect of one’s life, lending valid concern for the psychosocial wellbeing of those afflicted. These concerns are particularly well founded in adolescents, due to the number of changes they already manage within their developmental stage (Zebrack, 2011). This project examines the usefulness, accessibility, and utilization of multiple psychosocial interventions for adolescent oncology patients (AOPs) and the importance of peer interaction within them.

There has been significant decrease in the terminality of childhood cancer, which has increased the amount of research on the quality of life of children with cancer (Shama & Lucchetta, 2007). Moreover, this shift necessitates a need to focus on the psychosocial wellbeing of children living with cancer as oppose to children dying with cancer (Van Dongen-Melman & Sanders-Woudstra, 1986). Research has found that anxiety, depression, negative body image, and low self-esteem have been correlated to childhood cancer (Merrill et al., 2007; Patenaude & Kupst, 2005). Though studies show that the psychosocial state of pediatric cancer long-term survivors is relatively unimpaired, the many associated risks are still of great concern for the psychosocial wellbeing of children receiving treatment (Shama & Lucchetta, 2007).

Chronic illnesses such as cancer can often result in some form of social isolation, due to frequent hospitalization and physical inability to partake in conventional adolescent activities (Zebrack, 2011). Due to this isolation, developmental milestones can be much more difficult to achieve for AOPs (Zebrack, 2011). Additionally, adolescent’s
strong desire to gain social acceptance heightens the implications of their atypical adolescent experience (Cassano, Nagel, & O’Mara, 2008; Shama & Lucchetta, 2007). Peers often serve as a support system for these patients, lending value to their inclusion in the treatment process (Cassano et al., 2008; Ritchie, 2001). Furthermore, evaluations indicate positive outcomes from psychosocial interventions that promote interaction between AOPs (Cassano et al., 2008; Meltzer & Rourke, 2005).

Moreover, AOPs have different coping abilities and developmental demands than younger children (Barrera et al., 2003). Despite their differences, they are often cared for together in pediatric settings, which utilize a nurturing and authoritative approach that can easily clash with the developmental needs of adolescents (Freyer & Kibrick-Lazear, 2006). Because of their unique needs and abilities, adolescent specific oncology research is valuable. However, there is limited empirical evidence regarding the efficacy of adolescent psychosocial care (Seitz, Besier, & Goldbeck, 2009; Zebrack, Mathews-Bradshaw, & Siegel, 2010). Additionally, there is a lack of research regarding the accessibility to and utilization of psychosocial services for AOPs.

**Background of the Problem**

Much research has shown that the diagnosis of childhood cancer affects the psychological and social well being of a child (Kazak, Alderfer, Streisand, et al., 2004; Merrill et al., 2007; Patenaude & Kupst, 2005). However, with the drastic increase in survival rate, current research has been greatly devoted to the psychosocial impact on long-term survivors of childhood cancer. The shift in research focus gives reason to
further study the psychosocial effects of children who are not yet survivors of this chronic illness.

In addition, the recent advancements in medicinal treatments lengthen the time period a child is dealing with cancer (De Bolle, De Clercq, De Fruyt, & Benoit, 2008; Shama & Lucchetta, 2007). Over the last thirty years, childhood cancer has shifted from an acute illness to a chronic one (De Bolle et al., 2008; Shama & Lucchetta, 2007). The National Cancer Institute (2008) reports that the rate of incidence for all childhood cancers has increased from 11.5 cases per 100,000 children in 1978 to 14.8 cases per 100,000 children in 2004. Simultaneously, the mortality rate of all childhood cancers has decreased over the same period with the five-year survival rate of 58.1 percent between 1975 and 1977 jumping to 79.6 percent between 1996 and 2003 (The National Cancer Institute, 2008).

A diagnosis of cancer in a child no longer means they are certain to be terminal. Rather, a child’s experience of being sick with cancer is prolonged due to the recent advancements in medicine. This lengthening of process is ultimately a good thing because it has increased the overall survival rate. However, it also lends reason to research the psychosocial impact of children living and still battling with cancer as well as the effectiveness of interventions in addressing these issues.

Furthermore, adolescence is a crucial and difficult developmental time period. Adolescents are overwhelmed with the need to form their identity and independence as well as gain social acceptance (Zastrow & Kirst-Asham, 2010). These challenging developmental tasks exacerbate the psychosocial impact of cancer for adolescents in
comparison to their younger counterparts (Barrera et al., 2003; Zebrack, 2011). Frequent and lengthy hospital visits can isolate patients from their peers, which holds severe implications for the patient’s psychosocial development (Ramphal, Meyer, Schacter, Rogers, & Pinkerton, 2011). Hospital policy restrictions and physical and medical limitations make typical peer interactions much more inaccessible (Haluska, Jessee, & Nagy, 2002). Furthermore, a higher number of people are diagnosed with cancer between the ages of 15 and 25 than are children under the age of 15 (Bleyer, 2005).

Adolescence is a time in which peer interaction and social acceptance are paramount, signifying the value of including socialization in psychosocial interventions (Stevens et al., 2004; Zastrow & Kirst-Asham, 2010). Though it has been shown that adolescents value maintaining relationships with their healthy peers, they acknowledge the crucial benefits of relationships with fellow AOPs (Cassano et al., 2008; Shama & Lucchetta, 2007). Moreover, much literature supports this and acknowledges the psychosocial benefits from connection and interaction between AOPs (D’Agostino, Penney, & Zebrack, 2011; Meltzer & Rourke, 2005; Shama & Lucchetta, 2007).

Overall, there is a lack of knowledge among healthcare professionals regarding the unique cancer experience of adolescents (Ramphal et al., 2011). However, this issue is acknowledged in recent literature and efforts are being made to address it (Mathews-Bradshaw, Johnson, Kaplan, Craddock, & Hayes-Lattin, 2011). Because of this knowledge gap, there is limited empirical evidence for effective psychosocial interventions for AOP (Seitz et al., 2009; Zebrack, Hamilton, & Smith, 2009; Zebrack, Mathews-Bradshaw, et al., 2010). Systematic reviews have revealed that a minimal
number of evaluations are empirically validated (Meyler, Guerin, Kiernan, & Breatnach, 2010; Seitz et al., 2011). Compounding this is a lack of research regarding AOPs’ access to and utilization of psychosocial services. This lack of evidence makes it difficult to gauge the efficacy, availability, and utilization of psychosocial interventions for this population.

It seems apparent that AOPs’ unique childhood experiences combined with their developmental demands and need for peer interaction is vital when assessing appropriate and effective psychosocial interventions. This lends credence to assessing the psychosocial needs of this population as well as the role peer interaction may play in the effectiveness of interventions. Research on the existence and effectiveness of these services is valuable knowledge for patients, families and medical professionals, which validates further research of them.

**Statement of Research Problem**

Research acknowledges the psychosocial benefits of interaction between AOPs, which signifies the value of incorporating this in psychosocial services. However, the lack of empirical evidence supporting psychosocial intervention strategies for AOPs makes it difficult for specialists to be certain that they are delivering appropriate and effective care. Additionally there is minimal research on the accessibility to and utilization of psychosocial services for AOPs. Due to these research gaps it is challenging to gain a precise understanding of the services and interventions currently provided to AOPs. Moreover, it is difficult to accurately compare the efficacy of interventions that utilize interaction between AOPs and those that do not.
**Purpose of the Study**

This study aims to alleviate the gap in literature regarding the accessibility, utilization, and usefulness of psychosocial interventions for AOPs. Specifically, it intends to gain an understanding of the psychosocial services and interventions currently being provided to AOPs. Within this, the study intends to compare the perceived usefulness of interventions utilizing interaction between AOPs and those that do not. Its primary purpose is to build upon the limited evidence supporting specific strategies for adolescent oncology psychosocial care.

In an effort to do this, this study focuses specifically on the services offered and professional opinions in the Northern California area. It seeks to assess the types of psychosocial services offered to AOPs and their perceived usefulness in Northern California. It also plans to assess professionals perceived importance of peer interaction on the psychosocial wellbeing of AOPs. This studies secondary purpose is to highlight any discrepancies between Northern California’s service provision and the perceived success and/or importance of peer interaction within these services. This will be achieved by surveying social workers and child life specialists in Northern California that work closely with AOPs.

**Theoretical Framework**

Guiding this research are two applicable theoretical frameworks, the ecosystems theory and Erikson’s psychosocial theory. The ecosystems theory supports the overarching professional ethics of social work, which elucidate the validity of the
proposed research. Erikson’s psychosocial theory provides a relevant and guiding framework for human psychological and social development.

Zastrow and Kirst-Asham (2010) explained that the ecosystems theory coincides well with the *person-in-environment* perspective, a foundational concept in all social work practice. They explained that a *person-in-environment* perspective views humans as “constantly interacting with various systems around them” such as educational, political, religious, family, friends, and social services (p. 21). The authors described that the ecosystems theory combines aspects of systems theories and ecological perspectives, which examine the interaction between humans and their environment, and the affects they have upon human development.

The proposed research investigates the unique developmental experience of adolescents with cancer by examining their interactions with surrounding systems. By doing so, it examines the environmental and systematical affects on this target population, conferring the significance and relevance of the ecosystems theory. Furthermore the ecosystems theory takes into consideration coping and adaptation skills and acknowledges the interdependence between humans. Each of these components is necessary when examining the psychosocial wellbeing of adolescents with cancer (Zastrow & Kirst-Asham, 2010).

Seeing that the proposed research examines the psychosocial wellbeing of its target population, an understanding of their psychological and social development is necessary. Erikson’s psychosocial theory provides a framework that which guides the assumptions and findings of the proposed research. Zastrow and Kirst-Asham (2010)
explained that Erikson’s psychosocial theory categorizes the development of human personality within a sequence of developmental stages, which he refers to as crises. The authors explained the theories emphasis “on the role of the social environment in personality development” (p. 292). They also stressed the importance of coping with each of these crises to ensure positive and proper development.

In order to assess the psychosocial needs of adolescents and the appropriateness of interventions, one must first have an understanding of their development. Erikson’s psychosocial theory provides this insight by framing the developmental demands they may be encountering such as identity development and the desire for autonomy. Additionally, it emphasizes the importance of one’s social environment upon development, validating the peer interaction and social component of the proposed research. Lastly, having a grasp on the development of the target population creates for a better understanding of how systematical interactions (as explored in the ecosystems theory) may affect it.

**Definition of Terms**

The following terms are used throughout this project and are critical in accurately understanding the proposed research and relevant literature.

Adolescence - Adolescence is defined as the time period that which individuals transition from childhood into adulthood. Adolescence can be broken into three stages; early, middle, and late, and can be defined as spanning between the ages of 11 and 24 (U.S. Department of Health and Human Services, n.d.).
Psychosocial - “Describes the psychological (emotional) and social parts of a disease and its treatment. Some of the psychosocial parts of cancer are its effects on patients’ feelings, moods, beliefs, the way they cope, and relationships with family, friends, and co-workers” (The National Cancer Institute, n.d.-a).

Quality of Life (QOL) - “The overall enjoyment of life.” The perceived wellbeing and capabilities of an individual (The National Cancer Institute, n.d.-b).

Psychosocial Intervention - An action taken with the intention of improving the psychosocial wellbeing of an individual (The National Cancer Institute, n.d.-c).

Peer Interaction - For the purpose of this study peer interaction is defined as reciprocal exchange between adolescent oncology patients and other adolescents who have current or past experience with cancer.

Assumptions

The author of this study makes the following assumptions: 1) that pediatric oncology social workers and child life specialists have an understanding of the psychosocial needs and developmental demands of AOPs; 2) that pediatric oncology social workers and child life specialists are aware of the usefulness of the psychosocial interventions/services they offer.

Justification

This research is important and relevant to the field of social work because social workers and child life specialists often manage the psychosocial care of pediatric patients. This study provides guidance for them in evaluating their existing psychosocial services and developing effective ones. Having an understanding of the psychosocial
effects of peer interaction is valuable in referring patients to services and developing interventions for them. This research will further evidence the application of practices utilizing peer interaction and provide knowledge of how to effectively implement it. Furthermore, social workers are ethically required to utilize research evidence in their practice and the findings of this research further provide this for them (National Association of Social Workers, 2008).

Moreover, The National Association of Social Workers Code of Ethics explains that social workers should advocate for programs and services that meet the needs of their clients (National Association of Social Workers, 2008). This study will highlight any discrepancies between the success/importance of peer interaction in meeting AOPs’ needs and the services/interventions currently being offered to them. With this knowledge, pediatric oncology social workers can advocate for the development and implementation of services that are not currently provided to AOPs in Northern California. Ultimately, the findings from this research build upon the limited amounts of evidence in regards to this topic and create a basis for further investigation.
Chapter 2

REVIEW OF THE LITERATURE

The positive impact of support services on the quality of life and psychosocial wellbeing of adolescents with cancer and their families is a consistent finding within relevant research (Barlow & Ellard, 2004; Ritchie, 2001; Seitz et al., 2009; Zebrack & Isaacson, 2012). Because of this, many support services and interventions are offered and utilized within oncology centers and hospitals. Additionally, the unique developmental demands associated with adolescence significantly impacts an adolescent’s experience with cancer as well as the appropriateness of psychosocial intervention strategies (Ramphal et al., 2011; Zebrack, Mills, & Weitzman, 2007). The combination of these two facts implies the significance of researching effective and developmentally appropriate psychosocial interventions for this population.

Moreover, it is widely acknowledged that peer interaction and support has positive effects on the psychosocial wellbeing of AOPs (Meyler et al., 2010; Mitchell, Clarke, & Sloper, 2006). Research has yielded positive outcomes from psychosocial interventions that allow adolescents with cancer to meet, connect, and interact (Meltzer & Rourke, 2005; Stevens et al., 2004). The developmental time period of adolescence is marked by ones need to develop identity and body image, gain autonomy and social acceptance, and interact with peers (Ritchie, 2001; Zebrack, 2011). These developmental demands can make it difficult for adolescents with cancer to develop appropriately in comparison to their younger counterparts (Barrera et al., 2003). Despite their critical
differences, younger children and adolescents with cancer are often combined when cared for and researched.

Furthermore, there is minimal research on the efficacy of psychosocial interventions for adolescent oncology patients. Evidenced-based interventions are rare due to the lack of standardized outcome measures (Kazak et al., 2007; Seitz et al., 2009). This lack of empirical evidence lends credence to further examination of this topic. The following review explores the current literature and research regarding this notion. It begins by exploring the psychosocial needs and issues of adolescent oncology patients and then examines the existing services aimed at meeting these needs, and the role of peer interaction within them.

**Psychosocial Needs of Adolescent Cancer Patients**

Adolescence is the transitional time period between childhood and adulthood (Zastrow & Kirst-Asham, 2010). The physical, mental and social process of maturing during this period entails drastic changes, many of which are difficult for youth to cope with. This surge of development can be difficult to manage, often making adolescence a trying time for one’s psychological wellbeing (Evan & Zeltzer, 2006; Zastrow & Kirst-Asham, 2010). This difficulty applies to the adolescent population as a whole however, is compounded by the physical and psychosocial impact of cancer treatment.

**Identity Development**

Adolescence is distinguished by the personal and social demand to form one’s identity (Freyer & Kibrick-Lazear, 2006; Seitz et al., 2009; Zastrow & Kirst-Asham, 2010). It is acknowledged that identity development is a crucial and healthy milestone
within adolescence, which occurs within a social context and demands peer interaction (Shama & Lucchetta, 2007; Zebrack, 2011). Zastrow and Kirst-Ashman (2010) describe adolescence as a time period when teenagers define themselves and become comfortable with definition.

The formation of one’s identity includes several factors, such as, sexuality, career choice, future-oriented goals, self-esteem, and body image (Bolte & Zebrack, 2008; Zastrow & Kirst-Asham, 2010; Zebrack, 2011). Research has shown the negative impact cancer treatment can have on these elements of identity (D’Agostino et al., 2011; Patenaude & Kupst, 2005; Zebrack, 2011). Treatment drastically affects ones attendance at school and conventional social gatherings as well as ones physical capability to partake in typical teenage activities (Shama & Lucchetta, 2007). This isolation alters the social context in which identity development takes place.

Topics such as, sexuality, fertility, and intimate relationships are common concerns for AOPs due to the fact that adolescence is marked by the achievement of reproductive maturity and thus, the pursuit of a sexual identity (Bolte & Zebrack, 2008; Shama & Lucchetta, 2007). A recent study surveyed adolescent and young adult (AYA) cancer patients and survivors preferences about supportive care services. Fifty seven percent of the 1,088 respondents identified that they had used or would like to have had counseling and advice about fertility and sexuality issues (Zebrack et al., 2009).

The possibility of issues such as, decreased libido, reproductive potential, and orgasm intensity can make it challenging for adolescents to develop a healthy sexual identity. However, it can be difficult for care providers to breach these subjects due to the
young age of patients or their perceived maturity level (Bolte & Zebrack, 2008). For example, it can be necessary to discuss issues with patients and their families that seem inappropriate for the developmental stage of the child such as, sperm preservation. Despite this discrepancy, literature emphasizes the importance of breaching these topics in a sensitive and appropriate manner with adolescent patients in order to decrease the negative impact on their sexual health (Bolte & Zebrack, 2008; Evan & Zeltzer, 2006). The communication between care providers and AOPs about sexual health is especially important because adolescents can fail to acquire sexual knowledge from typical sources such as, school and their peers, due to the isolation ensued by treatment (Evan, Kaufman, Cook, & Zeltzer, 2006).

Additionally, a positive image of one’s physical self is an essential part of sexual health. During a time in which body image is extremely important, AOPs can find it difficult to develop a positive one, due to the many side effects of cancer treatment. Temporary and permanent hair loss, weight changes, scaring, and limb amputation are each potential side effects of cancer treatment and can negatively impact ones body image (Bolte & Zebrack, 2008). Moreover, body image and sexual identity are highly contingent on social interaction and the acceptance of peers. Isolation from their peers due to frequent hospitalization and physical limitations can make it difficult for adolescents to develop the skills and confidence to initiate intimate relationships (Evan et al., 2006). Additionally, their need for social acceptance can be negatively impacted because they often feel ‘different’ than their peers due to the physical and emotional tolls of cancer (Evan et al., 2006; Ramphal et al., 2011).
Furthermore, a central component of adolescence is the need to make goal-oriented decisions. This becomes increasingly difficult for AOPs due to the threat of mortality. Being unable to appropriately develop life goals such as, career choice, education, and family planning negatively impedes AOPs’ development. Literature stresses the importance that care providers initiate conversations with AOPs about their future goals and the implications cancer may have on it (Ritchie, 2001; Zebrack, Chesler, & Kaplan, 2010; Zebrack & Isaacson, 2012). This need to make future-oriented goals stems from adolescents yearning for autonomy.

**Autonomy**

In addition to identity formation, adolescence is marked by the desire to gain independence and autonomy (D’Agostino et al., 2011; Zastrow & Kirst-Asham, 2010). However, a diagnosis of cancer poses a unique and genuine threat on this developmental demand. Cancer treatment increases one’s dependency on their caregivers, conflicting with adolescents desire for independence (Ritchie, 2001; Seitz et al., 2009). Caregivers find themselves uncertain about AOPs’ capacity to adequately comprehend their diagnosis while AOPs find themselves both comforted and anxious about their imposed dependence (Drybrough, Frid, Vitko, Vlach, & D’Agostino, 2006).

This reality is noteworthy in evaluating appropriate treatment. Clark et al (1992) examined this when they researched the therapeutic effects of spontaneous interaction between adolescent cancer patients and their peers. They noted the positive effects of allowing teen cancer patients to achieve a spontaneous and supportive interaction. This spontaneity is an aspect of teenage life that assists in fulfilling adolescent’s desire for
independence. It is also something that can be difficult to maintain during treatment. Additionally, AOPs have reported the value they found in being able to perform tasks on their own during treatment such as, changing their own dressings and giving their own injections (Drybrough et al., 2006). However, appropriately respecting an AOP’s desire for autonomy during treatment can be a challenging task for care providers.

Literature has shown the importance of respecting adolescents desire for independence as well as being cognizant of their cognitive limitations (Drybrough et al., 2006; Ritchie, 2001; Zebrack & Isaacson, 2012). Though it is developmentally important to allow AOPs a chance to make decisions, operate independently, and be enlightened about their health condition, it is also critical to realize the difficulty they have in fully comprehending the consequences of their actions (Ritchie, 2001; Zebrack & Isaacson, 2012). Because of this, it is important that when physicians and caregivers attempt to respect an AOP’s autonomy that they understand their cognitive immaturity.

Moreover, due to their limited life experience, adolescents may not possess the skills necessary to effectively cope with the challenges ensued by cancer. It is important that physicians provide honest and open communication with AOPs while not imposing expectations that are beyond their cognitive capabilities (Drybrough et al., 2006; Evan & Zeltzer, 2006; Zebrack & Isaacson, 2012). Due to these factors, it can be challenging for care providers to determine the most developmentally appropriate approaches for care. A universal model for this does not exist, making it necessary for healthcare professionals to be attuned to the varying maturity levels and individual needs of each patient.
(D’Agostino et al., 2011). This challenge is exacerbated by the limitations of the current binary healthcare system.

Our current healthcare system is divided into two main populations, adult and pediatrics, making it challenging to account for the unique needs of adolescents (Bleyer, 2005; Drybrough et al., 2006; Freyer & Kibrick-Lazear, 2006). Each system of care employs a different approach. Pediatric settings utilize a nurturing and dictatorial approach while adult settings emphasize collaboration and empowerment (Freyer & Kibrick-Lazear, 2006). Because adolescence marks the transition between these two populations, AOPs require a unique combination of these two approaches. However, they are commonly cared for in pediatric settings and due to the variance in these environments, an flawless model for their care does not exist (D’Agostino et al., 2011).

Furthermore, many AOPs are required to transition from a pediatric system of care to an adult one at some point during treatment. The stark differences between their two approaches combined with the developmental demands of adolescence, makes it paramount that health care providers facilitate a smooth and successful transition (Bleyer, 2005; Freyer & Kibrick-Lazear, 2006).

This transition further signifies the importance and need for pediatric healthcare professionals to employ an approach that accounts for adolescent’s need for autonomy. By neglecting this need, a young adults transition into an adult system of care after receiving treatment as an adolescent could be shocking and detrimental. Common aspects of pediatric care can infantilize and exasperate older adolescents (Freyer & Kibrick-Lazear, 2006). Their nurturing approach can contradict AOPs’ desires for independence.
Moreover, having a significantly younger roommate can impede on adolescents being able to have typical teenage experiences such as, watching a movie with mature content or having uncensored conversations with their peers (Bleyer, 2005; Freyer & Kibrick-Lazear, 2006).

Furthermore, it has been shown that AOPs have poorer outcomes than younger children with cancer in terms of health related quality of life (Barrera et al., 2003; Seitz et al., 2011). This is believed to be largely due to treatment interfering with their need for autonomy (Barrera et al., 2003). Additionally, Manne and Miller (1998) found that AOPs often experience psychological distress due to conflicts with family members stemming from their need for independence.

The Psychological and Emotional Impact of Cancer

Research has shown that the psychosocial well-being of long-term childhood cancer survivors is relatively unimpaired (Shama & Lucchetta, 2007). In fact, literature exists on the positive psychosocial outcomes of a childhood cancer experience. An increase in psychological resiliency, sense of compassion, empathy, and the development of new values have been noted as psychological strengths of adolescents who experienced cancer (Evan & Zeltzer, 2006; Parry & Chesler, 2005). However, literature reveals that despite these positive outcomes for long-term survivors, there is still a great concern for the psychological wellbeing of adolescent cancer patients during and soon after treatment (Kazak, Alderfer, Rourke, et al., 2004; Merrill et al., 2007; Seitz et al., 2011).
Seitz et al (2009) framed the psychological needs of adolescent cancer patients well when they acknowledged the duality of their stressors. They explained that not only do teenage cancer patients have to deal with the physical and social invasiveness of treatment but also with the demands and stressors of transitioning from childhood into adulthood. Many of the developmental factors already discussed such as, sexual health, identity formation, independence and body image affect the psychological wellbeing of AOPs (Evan et al., 2006).

Merrill et al (2007) found that children who undergo tests for cancer were 89% more likely to experience anxiety and/or depression than those that do not. This study showed that the mere threat of cancer places children at a higher risk of experiencing psychological distress. They also found children undergoing cancer workups or treatment are at a higher risk for anxiety and depression if either or both of their parents experience depression and/or anxiety. Seitz et al (2011) supported this notion when they found that long-term survivors of adolescent cancer are less satisfied with their health-related and general quality of life, reflecting an increase in psychological distress.

Furthermore, the negative effects of cancer on an adolescent’s self-esteem is noteworthy (Evan et al., 2006; Patenaude & Kupst, 2005). Evan, Kaufman, and Zeltzer (2006) define self-esteem as the degree to which an individual is fond of himself or herself. They also note that the process of self-esteem development is highly contingent upon an individual’s interaction with his or her environment and is correlated with ones ability to form their identity. Thus, the challenges AOPs face in identity formation pose a significant threat to their level of self-esteem.
Additionally, a notable existence of post-traumatic stress symptoms (PTSS) has been found in adolescent cancer survivors (Kazak, Alderfer, Rourke, et al., 2004; Kazak, Alderfer, Streisand, et al., 2004). Kazak, Aderfer, and Rourke et al (2004) found that 50% of adolescent cancer survivors fulfilled the criteria for the re-experiencing symptoms (Cluster B) for post-traumatic stress disorder (PTSD) while 29% fulfilled the criteria for the arousal symptoms (Cluster D). Overall, they found that 78% of their sample population fulfilled at least one cluster of symptoms for PTSD. These findings display the importance of delivering effective psychological interventions for AOPs that take into account their unique challenges.

**Intellectual Needs & Technology Factors**

Likely stemming from adolescents desire for autonomy, research has found that many AOPs prioritize the importance of effective, appropriate, and open communication with healthcare providers (D’Agostino et al., 2011; Drew, 2007; Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). Barlow and Ellard (2004) advocate for the benefits of children with chronic disease assuming more active role in their care and discuss the effectiveness of psycho-educational interventions. Due to adolescents need for autonomy and independence, communication patterns between providers and patients have potential to increase the psychosocial wellbeing of AOPs. Drew (2007) found that a third of long-term childhood cancer survivors were dissatisfied with the amount of information they received from their physicians about the long-term effects of cancer. Moreover, research has found that adolescents and children with chronic illness identify websites and web-
based chat rooms as a valuable resource for support and knowledge (Drew, 2007; Kyngäs, 2004).

Schiffman, Csongradi, and Suzuki (2008) found that adolescent and young adults with cancer desire the use of websites that offer cancer related information and opportunities to meet and connect with other young people in similar situations. They also found that their respondents spent an average of two hours on the Internet each day, highlighting a noteworthy discrepancy. Despite their respondents frequent use of the Internet and desire for internet-based cancer resources, over half of them could not identify a cancer-related website. The authors were able to identify the existence of 27 AYA cancer websites. Schiffman, Csongradi, and Suzuki’s (2008) findings hold significant implications for providers delivering psychosocial care for AOPs. The use and management of Internet resources has potential to serve as a developmentally appropriate and effective psychosocial intervention for AOPs (D’Agostino et al., 2011; Zebrack & Isaacson, 2012).

Moreover, Zebrack, Chesler, and Kaplan (2010) found that AYA’s with cancer identified the psychosocial benefits of positive and effective communication patterns. They also found that AYA’s valued when physicians took the time to directly address their personal needs, concerns and questions. Drybrough et al (2006) supported this notion when they describe the value AOPs found in receiving information directly from their physicians as oppose to their parents. They also emphasized the importance of care providers understanding the cognitive abilities of adolescents. They elucidate the fact that though AOPs demand more from their physicians than their younger counterparts, their
ability to process information is still developing. Because of this, it is important that care providers deliver information that is age and developmentally appropriate (Drybrough et al., 2006; Mitchell et al., 2006; Ritchie, 2001).

**Social Acceptance and Interpersonal Relationships**

The many developmental demands already described are directly affected by adolescents desire for social support, acceptance and relationships (Zastrow & Kirst-Asham, 2010). Literature shows the disruption cancer treatment can cause in achieving these social goals (Cassano et al., 2008; Patenaude & Kupst, 2005; Zebrack, 2011). Several factors such as, frequent hospitalization, absence from school, physical limitations, and maturity level differences can make it difficult for AOPs to stay connected with peers, maintain and develop interpersonal relationships, and gain the social acceptance they yearn for (Cassano et al., 2008; Eiser, 1998; Patenaude & Kupst, 2005; Shama & Lucchetta, 2007; Zebrack, 2011).

Moreover, knowing when it is appropriate to disclose their diagnosis and how much information to provide about it is challenging for AOPs. This exacerbates their difficulty in forming and maintaining interpersonal relationships (Zebrack, 2011). Compounding these challenges are the affects of other developmental demands such as, body image, identity development, and autonomy, each of which directly affect AOPs’ social abilities and confidence (Shama & Lucchetta, 2007; Zebrack, 2011).

Research findings reveal the difficulties that adolescent cancer patients encounter in attaining a time and space that allows for conventional peer interaction (Meyler et al., 2010; Mitchell et al., 2006). Hospital regulations and physical restrictions make it
difficult for adolescent cancer patients to find the space and time to meet and interact with other teens, whether it be with their healthy counterparts or fellow cancer patients (Meyler et al., 2010; Mitchell et al., 2006). Moreover, AOPs fear that they will be rejected by their peers and perceive themselves as less socially competent (Evan & Zeltzer, 2006; Shama & Lucchetta, 2007). It has also been shown that young adults who have survived childhood cancer are more impaired in social and romantic relationships than their healthy peers (Evan & Zeltzer, 2006). These factors raise concern for adolescent cancer patients to fulfill their developmental need for social interaction and acceptance.

In addition to adolescents developmental need for social relationships, literature highlights the positive benefits supportive relationships have on an adolescents ability to cope with cancer (Decker, 2006; Shama & Lucchetta, 2007; Zebrack, 2011). Furthermore, Haluska, Jessee, and Nagy (2002) found that AOPs’ satisfaction with support increases with the number of supports they have and they identify similar sources of support to their healthy counterparts. Sources of support have been identified by AYA’s as healthy peers, other adolescents with cancer, classmates, nurses, physicians, and family (Kyngäs, 2004; Shama & Lucchetta, 2007; Zebrack, 2011). These factors highlight the importance that healthcare providers allow and encourage AOPs to stay connected with their peers, develop interpersonal relationships, and maintain as normal of a life as they can (Ritchie, 2001).
Psychosocial Interventions and the Role of Peer Interaction

Having a comprehension of the psychosocial needs of adolescent oncology patients allows for a better understanding of the interventions aimed at meeting these needs. The lack of evidence-based psychosocial care for AOPs lends credence to further examination of existing psychosocial interventions (Seitz et al., 2009). The following section explores the efficacy of current psychosocial intervention strategies and the factors influencing this. It begins by examining the role of peer interaction within psychosocial interventions and then explores existing intervention strategies. It then examines the empirical data supporting these strategies and ends with a discussion about their accessibility and utilization.

The Role and Impact of Peer Interaction

Much literature acknowledges the positive psychosocial effects of connection and interaction between AOPs and summarizes the impact this has on healthcare professionals and environments (Cassano et al., 2008; D’Agostino et al., 2011; Shama & Lucchetta, 2007; Stevens et al., 2004; Zebrack, 2011). D’Agostino et al., (2011) stressed the developmental importance of adolescent cancer patients to attain healthy peer interactions. Because of the disruptions cancer treatment has on the achievement of developmental milestones, the authors emphasized the criticalness for healthcare environments to foster healthy peer interaction.

Peer interaction decreases the sense of isolation felt by an adolescent cancer patient and fosters the maintenance and development of support systems (Cassano et al., 2008; Haluska et al., 2002; Seitz et al., 2009). Ritchie (2001) stressed the positive effects
of support systems on the adaptation skills of adolescent cancer patients. She acknowledged the prominent role peers could have in these support systems. Additionally, she explained that sometimes healthcare professionals attempt to fulfill a supportive role for adolescent patients as oppose to fostering the already existent ones and facilitating the development of new ones. A significant amount of research supports this notion and stresses the importance of establishing a healthcare environment that allows patients to maintain interaction with their social support systems and delivers services that encourage AOPs to meet and interact (Cassano et al., 2008; Stevens et al., 2004; Zebrack, Bleyer, et al., 2006).

Regardless of whether or not it is their primary aim, many of the existing psychosocial intervention strategies utilize peer interaction. Moreover, many of their evaluations reveal that participants perceive the social aspect of these interventions as the most valuable part of them. Meltzer and Rourke (2005) summarize this well when they explain that perhaps research on the psychosocial benefits of specific interventions overlooks the main benefit of merely interacting with a similar peer group.

**Psychosocial Intervention Strategies**

Despite the lack of standardized outcome measures, there is much literature on existing psychosocial interventions for AOPs. One of the most common approaches is the facilitation of support groups. Research indicates positive psychosocial effects from peer support groups, particularly if they revolve around interactive activities (Barrera, Damore-Petingola, Fleming, & Mayer, 2006; Cassano et al., 2008; Mitchell et al., 2006). Barrera et al (2006) informally reviewed the outcomes of two group-based interventions
for AOPs in Ontario, Canada. One of the programs was based in a rural area, meets once a month, and is aimed at reducing social isolation for AOPs. The other program took place in an urban area and consists of eight two-hour sessions.

Both programs reviewed by Barrera et al included creative activities, such as art, drama, and social events. Each of the programs aimed to allow AOPs to have fun together. Formal discussion was encouraged and facilitated throughout the group meetings but was not the sole component. Though the programs have not undergone a systematic review, informal feedback from participating adolescents indicates positive effects in terms of received support and sustainable skill building. Research done by Roberts, Piper, Denny, and Cudeback (1997) on the affects of a support group utilizing group therapy techniques and psychoeducational strategies for young adults with cancer revealed similar results. The pretests and posttests indicated a significant increase in the psychological wellbeing of participants.

As mentioned, literature indicates that AOPs find support groups to be more effective and worthwhile if the meetings are activity-based (Cassano et al., 2008; Mitchell et al., 2006). This preference could be attributed to AOPs’ desires to maintain as much normalcy as they can and engage in social activities with their peers (Ritchie, 2001; Shama & Lucchetta, 2007). This is supported by Shama and Lucchetta’s (2007) evaluation of a Teen Outreach Program (TOP) that aimed to connect “teens with leukemia/lymphoma to one another, and to reconnect them back with their peers by engaging them in ‘normal’ events” (p. 99). This program created social events for adolescent cancer patients to attend such as field trips to a day spa for the girls and an
outing to a professional hockey game for the boys. Participants were allowed to bring a friend, creating a more comfortable environment for them while still fostering the development of new peer relationships.

This preference for activity-based support groups could also attribute to AOPs’ low rates of participation in conventional support groups. It has been found that AOPs have minimal interest in attending conventional support groups and desire partaking in normal teenage social activities (Mitchell et al., 2006; Zebrack & Isaacson, 2012). Mitchell, Clark, and Sloper (2006) supported this notion when their survey of 303 families revealed that only 17% of the young people with cancer had attended an organized support group and 73% had no desire to attend one. However, nearly all of those who attended a support group enjoyed their experience and indicated a preference for activity-based meetings.

The positive feedback gained from these program evaluations reveals the potential impact of activity-based support programs. Zebrack and Isaacson (2012) explained this further when they noted that AOPs preferred type of support group is one that presents a social networking opportunity. Activity-based groups create a time and space for adolescent cancer patients to interact with their peers as well as create a sense of normalcy within their lives. The positive psychosocial effects of recreational-based activities and oncology-specific camps further support the efficacy of this strategy (Meltzer & Rourke, 2005; Meyler et al., 2010; Zebrack & Isaacson, 2012)

Meltzer and Rourke (2002) evaluated the psychosocial effects of an adolescent cancer specific summer camp. Their findings showed that adolescents reported a higher sense of self-competence and acceptance while at camp. Meltzer and Rourke (2002)
highlighted the benefits of allowing children with cancer an opportunity to compare themselves socially with a similar peer group. They acknowledged that the positive psychosocial outcomes of disease specific summer camps could be attributed mainly to the peer interaction they provide. Wu, Prout, Roberts, Parikshak, and Amylon (2011) found similar results in their evaluation of cancer-specific camps. They found that overall children were highly satisfied with the recreational activities, peer support, and respite the camp experience provided them. Qualitative data also revealed that campers appreciated the sense of belonging they experienced while at camp.

Furthermore, a brief and informal evaluation of an adventure therapy program for adolescents in cancer remission displayed positive psychosocial outcomes (Stevens et al., 2004). Adventure therapy focuses on the accomplishment of a challenging physical outdoor experience and has primarily been used in working with adolescents with mental health and behavioral issues. Qualitative data was collected by videotape and interviews during a 10-day mountaineering adventure with eleven AOPs. Four major positive aspects of the trip emerged: developing connections, togetherness, rebuilding self-esteem, and creating memories (Stevens et al., 2004). Participants reported an increase in self-esteem and emotional connection and an affirmed sense that they were not alone in their experience with cancer (Stevens et al., 2004). It has been noted that this sense of emotional connection between AOPs has been achieved through Internet-based resources as well.

In recent years, the benefits of technology-based psychosocial interventions are represented in relevant literature. A recent study showed that 95% of young adults who
were diagnosed with cancer between the ages of 15-35 reported that they had used or wanted to use Internet sites that offered appropriate cancer information and support (Zebrack, 2008). This signifies the potential efficacy of utilizing Internet-based resources for psychosocial interventions. This is reinforced by the recent finding that AYA’s with cancer spend an average of two hours on the internet each day (Schiffman et al., 2008).

Additionally, adolescents with chronic diseases identified Internet chat rooms, informational websites, and videos as valued sources of support (Kyngäs, 2004). The use of video in a psychosocial intervention aimed at increasing psychosexual development for AOPs in Canada also proved to have positive outcomes (Seitz et al., 2009). Moreover, it has been shown that adult cancer patients who use the Internet as a source of information have higher self-efficacy for assuming a more active role in their treatment than those who didn’t utilize Internet informational resources (Zebrack et al., 2009). Due to the technology savvy world that adolescents live in today, these results lend credence to the potential impact of technology-based interventions.

Technology can also play an important role in skill-building interventions for AOPs (Seitz et al., 2009). The Young Adult Survivor Conference is a 4-day conference aimed at providing cancer education and promoting self-advocacy skills for survivors of childhood, adolescent, and young adult cancer (Zebrack, Oeffinger, Hou, & Kaplan, 2006). Most participants identified that they valued the advocacy skills they gained during their time at the conference. However, a majority of attendees identified that they valued the opportunity to connect and socialize with other survivors the most (Zebrack, Oeffinger, et al., 2006).
Furthermore, Zebrack and Isaacson (2012) discuss the potential of utilizing cognitive behavioral therapy (CBT) techniques to change AOPs’ perceptions of their disease and thus decrease their psychological distress. CBT is an evidence-based practice based on the idea that people’s interpretation of events influences their behavior and psychological wellbeing. Despite the empirical data supporting it in other areas, little research exists on the effects of CBT on the psychosocial wellbeing of AOPs (Zebrack & Isaacson, 2012). This lack of standardized research is consistent across psychosocial interventions for AOPs as a whole, resulting in an absence of evidence-based practices (Kazak et al., 2007; Seitz et al., 2009; Zebrack, Mathews-Bradshaw, et al., 2010).

Evidence-Based Practices and Empirical Data

As shown above, preliminary and informal research exists that indicates positive outcomes for specific psychosocial interventions. However, there is an alarming lack of evidence-based practices and guidelines for the psychosocial care of AOPs (Kazak et al., 2007; Seitz et al., 2009; Zebrack et al., 2009; Zebrack, Mathews-Bradshaw, et al., 2010). Kazak et al (2007) attempted to apply psychology research findings to pediatric psychosocial care based on years of research within the department of clinical services at The Children’s Hospital of Philadelphia. Kazak et al (2007) provided an initial guideline for developing and evaluating psychosocial interventions for pediatric oncology patients and their families. They conclude that an evidence-based approach to psychosocial care for this population is still a lofty goal and stress the importance of collaboration between professional disciplines in order to achieve it. Both Furthermore, Kazak et al (2007) and
Penkman, Scott, and Pelletier (2006) note that deriving empirical data in support of interventions has the potential to extend the funding options for psychosocial care. Meyler et al.’s (2010) findings further supported the need for evidence-based practices (EBP) when their review of family-based psychosocial interventions in pediatric oncology found that few interventions were empirically validated. Furthermore, because AOPs are often studied under the umbrella of pediatrics, even less empirical research exists on adolescent specific psychosocial interventions. In Seitz et al.’s (2009) systematic review of psychosocial interventions for AOPs, only four studies incorporated defined outcome measures and were intended specifically for adolescents. Zebrack, Mathews-Bradshaw, and Siegel (2010) explained that this lack of age-specific research results in healthcare professionals relying on adult and children-based research for guidance regardless of its appropriateness. They emphasize the importance of obtaining empirical confirmation in order to create an evidence-based approach to adolescent psychosocial care.

Moreover, it is critical that future research accounts for the varying needs and types of families confronted by childhood cancer. In order to deliver effective psychosocial care, a multitude of evidence-based interventions are needed (Meyler et al., 2010; Mitschke, 2008). The dire need for empirical data within this field has significant implications for future endeavors. Efforts were made to address this need in 2006 when the LIVESTRONG foundation collaborated with the National Cancer Institute (NCI) and formed an Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG). The AYAO PRG was created to address the unique biological and psychosocial
impact of cancer for AYA’s and further the research on this topic (Mathews-Bradshaw et al., 2011). This is one example of an effort to establish a system of care that meets the needs of this underserved group.

Utilization and Accessibility of Psychosocial Services

Similar to the lack of EBP’s for adolescent psychosocial care, little research exists on the utilization and accessibility of psychosocial services for AOPs. Because of this, it is difficult to gain an accurate understanding of existing services. The minimal research that has been done on this topic reveals that many AOPs identify unmet psychosocial needs and a lack of services available to them (Zebrack et al., 2009, 2007). Moreover, there appears to be an underutilization by AYA’s of healthcare related services as a whole (Bleyer, 2005). This lack of service use is potentially exacerbated in areas where patients do not have access to specialized cancer care (Bleyer, 2005; Zebrack, Mathews-Bradshaw, et al., 2010). Issues such as geographical location and insurance coverage have potential to aggravate a patient’s access to services. These factors lend credence to further examination of AOPs’ utilization of and accessibility to psychosocial services.
Chapter 3

METHODOLOGY

This study explores the usefulness, accessibility, and utilization of various psychosocial interventions for AOPs and the role/importance of peer interaction within them. In order to do this, responses to an online questionnaire were collected. The methodology of this study is presented in this chapter.

Study Design

This project utilizes a descriptive research design by the use of a key-informant/experts survey. Descriptive research typically strives to collect the varying perceptions and experiences of individuals regarding a particular topic. Descriptive research is an effort to better understand a topic that has already been explored (Yegidis, Weinbach, & Myers, 2012). This research project collected the varying perspectives and experiences of pediatric psychosocial specialists in Northern California.

The opinions of hospital professionals who are involved with adolescent oncology patients were gathered through an online questionnaire. Respondents were asked to provide their perceptions of the psychosocial needs of this population and the role of peer interaction in meeting these needs. Additionally, they were asked to describe and evaluate the effectiveness of the internal psychosocial services they provide as well as the external psychosocial services they refer-out to. The participants of this research consist of pediatric oncology Social Workers and Child Life Specialists in the Northern California area. This researcher plans to document whether or not there is a discrepancy between the
values and perceptions of these professionals and the existence and/or provision of services.

Both qualitative and quantitative data were collected in this research project. A combination of open-ended qualitative questions and multiple-choice close-ended questions were used within the instrument. The multiple-choice questions utilized both a nominal and ordinal level of measurement.

**Sampling Procedures**

This project utilized a purposive convenience sample of hospital professionals who work closely with adolescent oncology patients. Pediatric oncology Social Workers and Child Life Specialists from Northern California hospitals providing pediatric oncology care were contacted through professional and personal contacts to participate in an online survey. This researcher employed a snowball sampling technique by emailing personal contacts and requesting their participation and/or assistance in passing the request on to other professionals in the field (Appendix A).

This researcher aimed to recruit at least one pediatric oncology Social Worker and a Child Life Specialist (that works with oncology patients) from each of the three specialized children’s cancer centers in the Sacramento area. In addition to this, the researcher aimed to recruit as many pediatric oncology Social Workers and Child Life Specialists as possible from the other three centers in Northern California. These recruitment efforts yielded a sample size of 29. It is difficult to estimate the population size of this study due to privacy issues and varying hospital compositions. However, it is estimated that this sample size represents a significant portion of the population based off
of the small number of hospitals providing pediatric oncology care in the Sacramento region and San Francisco Bay Area.

Each participant in this research was voluntary and initially contacted through email with an explanation of the purpose and methods of the study as well as the ethical measures of the research. Participants were not compensated in anyway for their participation in this study. Each participant was emailed a link to the online questionnaire at SurveyMonkey.com. This researcher is not professionally, personally, or financially affiliated with the participating agencies. Therefore there was no conflict of interest as a researcher.

Each participant was required to read and indicate consent to participate in the research prior to completing the online questionnaire. A statement of consent was presented upon following the link to the survey (Appendix B). Participants were required to indicate that they had read the statement of consent and agree with it before beginning to answer the questionnaire. Implied consent is deemed as an appropriate form of consent for this research due to the lack of vulnerability among the population being surveyed (Royse, 2007). Moreover, subjects were only asked to provide their professional knowledge and opinions. No personal or identifiable information was requested.

Data Collection Procedures

Each participant was initially contacted through an email, which discussed the purpose of the research as well as the privacy protective measures of it such as agency and individual anonymity, voluntary participation, and data security measures. Data was transferred in an encrypted format to ensure that the responses could not be decoded and
linked back to the respondent. The highest level of data encryption was used, within the limits of availability and feasibility. The online questionnaire was administered through SurveyMonkey.com. SurveyMonkey.com is a reputable online survey tool. It allowed the researcher to use Secure Sockes Layer (SSL) to enable https encryption. SurveyMonkey’s website uses cryptographics systems for security of connections between the respondents and the server (SurveyMonkey, 2012). Data was exported from SurveyMonkey.com and integrated into Microsoft word processing and Excel computer programs.

**Instruments**

This research was conducted through an online questionnaire constructed by this researcher (Appendix C). The study’s research questions and findings within the current literature guided the development of the questionnaire, which utilized a table of specifications (Yuen, Terao, & Schmidt, 2009). The chief domains included were provision, level of peer interaction, accessibility, and utilization of varying psychosocial interventions.

The questionnaire consisted of multiple-choice and open-ended questions regarding the existence and usefulness of psychosocial services offered for adolescent oncology patients. It begins with two questions regarding the demographics of participants and their expertise within the field. However, no identifiable information was requested from the participants. This is followed by five multiple-choice questions regarding the psychosocial needs of this population and the role of peer interaction within them. Respondents were then asked to answer seven multiple-choice questions regarding the delivery and effectiveness of ten different types of psychosocial
services/interventions. Space is also provided for respondent’s to include and evaluate any other type of psychosocial services that they deem relevant. The survey ended with two open-ended questions regarding the respondent’s professional opinion about the provision of psychosocial services within their agency. Please see Appendix B for a copy of the questionnaire.

**Data Analysis**

Each questionnaire received was coded for identification purposes. The qualitative data was exported to and analyzed through a word processing program in order to eliminate the chance of the respondent’s wording being recorded incorrectly. To ensure its reliability, this researcher and a colleague independently performed content analysis of the qualitative data. This colleague has completed the same graduate level coursework as this researcher and understands the relevant ethical considerations. Each researcher categorized the survey questions and then documented the themes found among the responses. The frequency of these themes was counted and concrete examples of them, such as quotations from answers, were documented. After both researchers completed their individual analysis, they met and developed a consensual interpretation of the data. The quantitative data was exported into an Excel computer program for analysis. This program utilized descriptive and inferential statistics for a precise and accurate analysis.

Guiding the analysis was four key questions, beginning with the perceived importance of peer interaction in the psychosocial wellbeing of AOPs and the usefulness of interventions involving peer interaction and those that do not. Following this was the internal provision of and external referrals for psychosocial interventions. Lastly, were
the relationships and/or discrepancies between the perceived usefulness of interventions and provision, levels of accessibility, and utilization.

**Protection of Human Subjects**

An application for this research was submitted to the Committee for the Protection of Human Subjects from the Division of Social Work at California State University, Sacramento. The committee approved the study with an “exempt” status, acknowledging that the research did not pose any harm to its participants (Appendix D). The approval number is 12-13-034.

Each participant was informed of the privacy protective measures of the research such as agency and individual anonymity, voluntary participation and data security measures. The participants were not asked to provide any identifiable information such as agency affiliation or personal details within the survey, to ensure their anonymity. Moreover, data was transferred in an encrypted format to ensure that the responses could not be decoded and linked back to the respondent.
Chapter 4

RESULTS

This chapter summarizes the findings from an online questionnaire completed by child life specialists and oncology social workers who work closely with AOPs in Northern California. The study is intended to gain an understanding of the psychosocial services and interventions currently being provided to AOPs and compare the perceived usefulness of interventions utilizing peer interaction and those that do not. Moreover, this study intended to highlight any discrepancies between Northern California’s service provision and the perceived success and/or importance of peer interaction within these services. Analysis of the data collected from this study is presented and supported through various graphs, charts, and tables. The chapter begins with an overview of the overall findings, including the sample size and demographics of participants. Specific findings are then presented, including significant patterns, discrepancies, and relationships found. Lastly, a brief summary of the overall analysis is provided.

Overall Findings

The online questionnaire yielded 29 responses from child life specialists and oncology social workers employed by hospitals in the San Francisco Bay Area and Sacramento region of Northern California. Ten of the participants completed only half of the questionnaire, and 19 completed all of it. As the partially completed questionnaires still yielded useful data, the researcher included these partial responses in analysis. Due to this, the sample size (n) varies throughout the analysis depending on which portion of the questionnaire is being examined. Due to privacy and anonymity issues, it was
impossible to estimate the population size of this study. Hospital employee demographics are often difficult for the general population to access. Moreover, hospitals organize employee duties differently and AOPs can be treated in both adult and pediatric units. These factors make it difficult to accurately estimate the number of social workers and child life specialists involved with AOPs.

**Respondents and Profession**

Thirteen (44.8%) of the 29 participants identified themselves as pediatric oncology social workers while 15 (51.7%) identified themselves as child life specialists (Figure 1). One (3.4%) participant identified themselves as an adult oncology social worker. Each participant was required to read and indicate consent to participate in the research, wherein which they were instructed to only complete the survey if they work closely with the target population (AOPs). Due to this, the researcher included responses from the participant that identified as an adult oncology social worker in the analysis. The researcher acknowledges that the participant’s professional title may not accurately reflect the entirety of the population they serve.

**Respondents and Geographic Location**

At the end of the questionnaire, participants were asked to identify the geographic region in which they were most familiar with service provision. Of the 19 participants that completed the questionnaire, 6 (31.6 %) reported that they were more familiar with the services in the Sacramento region. Thirteen participants (63.2%) reported that they were more familiar with services in the San Francisco Bay Area and one participant
(5.3%) reported that they were familiar with both (Table 1). Due to the difficulty this final response posed for analysis, it was excluded from the analysis.

These data allowed the researcher to assume that the identified area indicated the location of respondent’s agencies. The study yielded a larger representation of professionals in the San Francisco Bay Area. The researcher speculates this could be due to the size of the hospitals in this area. The specialized pediatric cancer centers located in the San Francisco Bay Area are notably larger than the ones located in the Sacramento region, making it likely that they employ a larger staff.

**Distribution of Profession and Location**

Eight of the 14 social workers completed the entire questionnaire and identified a geographic location wherein which they are more familiar with service provision. Four of those reported that they were more familiar with services in the Sacramento region and three reported that they were more familiar with services in the San Francisco Bay Area (Table 1). As stated, one social worker reported that they were familiar with services in both areas, excluding them from analysis (n=18). The sample yielded a relatively even representation of social workers in both geographic locations.

Of the fifteen Child Life Specialists, 11 completed the entire questionnaire and identified a geographic location wherein which they are more familiar with service provision. Two of these reported that they are more familiar with services in the Sacramento region, while 9 reported that they are more familiar with services in the San Francisco Bay Area (Table 1). The sample yielded an uneven representation of Child Life
Specialists between the two geographic locations with a greater representation of the San Francisco Bay Area.

The researcher speculates that this could be due to the size of the hospitals in the Bay Area, which would allow them to employ a larger child life team. Additionally, it is possible that some hospitals assign specific child life specialists to work with AOPs, while others allow the entire team to interact with them. This could increase the number of child life specialists eligible to participate in the study.

Figure 1. Distribution of respondents by profession
Table 1

*Distribution of respondents by geographic location and profession*

<table>
<thead>
<tr>
<th></th>
<th>Number/Percentage of Entire Sample Size (n=29)</th>
<th>Sacramento Region (n=18)</th>
<th>San Francisco Bay Area (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
</tr>
<tr>
<td>Social Workers</td>
<td>14</td>
<td>48%</td>
<td>4</td>
</tr>
<tr>
<td>Child Life Specialists</td>
<td>15</td>
<td>52%</td>
<td>2</td>
</tr>
</tbody>
</table>

**Specific Findings**

The primary purpose of this study was to build upon the limited evidence supporting specific strategies for adolescent oncology psychosocial care. Its secondary purpose was to highlight any discrepancies between the provision of psychosocial services in Northern California and the perceived success and/or importance of peer interaction within these services. Specifically, this study aimed to assess the types of psychosocial services offered to AOPs, their utilization, and their perceived usefulness in Northern California. Additionally, it aimed to assess professional’s perceived importance of peer interaction on the psychosocial wellbeing of AOPs.

Findings related to the study’s purpose and aims are presented in this section, beginning with the perceived importance of peer interaction. Following this, is the perceived usefulness of various psychosocial interventions and the provision of these services both internally (organized and facilitated by hospital staff) and externally (referred out to other agencies). Within this, the usefulness of interventions utilizing peer
interaction is explored and the relationship between service provision and perceived usefulness is examined. Lastly, findings related to the utilization and accessibility of psychosocial services is presented and discrepancies between this and the perceived usefulness are explored.

**Importance of Peer Interaction**

Respondents were asked to rate how important they believe the role of peer interaction to be in the psychosocial wellbeing of AOPs. Nearly 90% of respondents rated it either important or very important (Figure 2). Additionally, respondents were asked how important they believe their agency rates the role of peer interaction in the psychosocial wellbeing of this population. Fifty-eight percent of respondents reported that they believe their agency rates the role of peer interaction as either important or very important while roughly 38% reported that they believe their agency rates it moderately important (Figure 2). According to a Spearman’s rank correlation test, the professionals’ ranking of the importance of peer interaction was moderately and positively correlated to their perception of their agencies’ ranking (P value = 0.002).

These findings highlight the positive correlation, though different, between the values of professionals and the perceived values of agencies. It was found that professionals rate the importance of peer interaction higher than they believe their agencies do. This disparity could be influenced by financial incentives. It is likely that interventions involving peer interaction are not as easily billable through private and public insurances in comparison to those that do not.
Furthermore, respondents were asked to identify which psychosocial areas they believe may be affected by a lack of peer interaction for AOPs. Respondents were given a list of eight different psychosocial areas drawn from the literature. Nearly 70% of respondents reported that all of the listed areas can be affected by a lack of social and peer interaction for AOPs (Figure 3).

Figure 2. Professionals’ vs. Perceived Agency Ranking of the Importance of Peer Interaction

Usefulness and Service Provision

Respondents were provided a list of ten different psychosocial interventions, all of which were drawn from the literature. Eight of these ten interventions involved peer interaction or had the potential to involve peer interaction while the other two do not involve peer interaction. Respondents were asked to rate the usefulness of each of these
interventions and indicate if they provided them internally (organized and facilitated by hospital staff) and/or referred patients to outside agencies for them.

Figure 3. Areas Affected by a Lack of Social or Peer Interaction

The interventions that do not involve peer interaction (family therapy and individual therapy) had the highest rates of being provided internally (Table 2). Eighty-four percent of respondents indicated that they provide individual therapy internally and 58% indicated that they provide family therapy internally. These findings could also be influenced by financial incentives. It is feasible that family therapy and individual therapy are more easily billable through private and public insurance providers. These two services were also rated among the top five most useful interventions. Eighty-four percent of respondents indicated that individual therapy is useful in addressing the psychosocial needs of AOPs while 89% indicated that family therapy is useful.
All seven of the interventions involving peer interaction were identified as useful by 68% or more of the respondents. The mean of the percentage of peer-based services identified as useful was 82%. However, findings showed that few of these services are provided internally (0–47%) and a higher percentage of professionals refer patients to outside agencies for them (28–100%). The mean of the percentage of agencies that provide peer-based interventions internally was 18% while the mean of the percentage of agencies that refer patients to outside agencies for these services was 64%. Oncology specific camps, social events, and out-of-town excursions were rated among the top five most useful interventions, with oncology specific camps rated as the highest overall. One hundred percent of respondents indicated that oncology specific camps are useful, while 83% of respondents indicated that social events and out-of-town excursions are useful.

**Interventions with the Most Positive Psychosocial Effects**

Findings from the qualitative data further support the quantitative data in regards to the usefulness of specific interventions. Eighty percent of respondents identified social events and/or activities with peers as a service/intervention they have found to be the most beneficial for the psychosocial wellbeing of AOPs. One respondent reported that “any activity that provides a forum for face to face peer interaction especially coupled with a fun activity” has shown to have the most positive psychosocial effects. Another respondent has found that “teen social events where the teens run the show and are able to develop their own networking support team made up by other teens” have the most positive psychosocial effects.
Moreover, 67% of respondents identified interventions involving peer interaction as an area of care that could be improved within their agency. This is congruent with findings from the quantitative data, which revealed that a low percentage of agencies provide peer-based interventions internally. Social events were found to be the most common peer-based intervention provided internally, with 47% of respondents indicating that their agency provides this. Support groups and therapeutic groups followed this, with 22% of respondents indicating that these were provided internally.

Table 2

*Perceived usefulness of interventions and rates of internal and external provision*

<table>
<thead>
<tr>
<th>Interventions that involve peer interaction</th>
<th>% Provided internally</th>
<th>% Referred</th>
<th>% reported as useful or very useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support groups</td>
<td>22</td>
<td>84</td>
<td>68</td>
</tr>
<tr>
<td>Social events/nights/outing</td>
<td>47</td>
<td>72</td>
<td>83</td>
</tr>
<tr>
<td>Therapeutic groups</td>
<td>22</td>
<td>28</td>
<td>80</td>
</tr>
<tr>
<td>Out of town excursions</td>
<td>0</td>
<td>63</td>
<td>83</td>
</tr>
<tr>
<td>Adventure/recreational outings</td>
<td>5</td>
<td>29</td>
<td>75</td>
</tr>
<tr>
<td>Oncology specific camps</td>
<td>16</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Oncology specific online networking</td>
<td>11</td>
<td>74</td>
<td>82</td>
</tr>
<tr>
<td>Interventions that may involve peer interaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psycho-educational groups</td>
<td>12</td>
<td>38</td>
<td>62</td>
</tr>
<tr>
<td>Interventions that don’t involve peer interaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual therapy</td>
<td>84</td>
<td>89</td>
<td>84</td>
</tr>
<tr>
<td>Family therapy</td>
<td>58</td>
<td>89</td>
<td>89</td>
</tr>
</tbody>
</table>
Usefulness, Utilization, and Accessibility

Respondents were also asked to identify the accessibility and utilization for each of the psychosocial interventions (Table 3). Findings revealed that a majority of professionals believe all that services are accessible to either some or most patients. The mean of the percentage of services perceived to be accessible by most/all patients was 40% while the mean of the percentage of services perceived to be accessible by only some patients was 46%. Fifty-nine percent or less of respondents reported that most/all patients utilize services other than oncology specific camps. Participants reported significantly higher rates of accessibility than utilization.

Overall, professionals perceive the utilization of services to be relatively low. A majority of professionals believe all services are utilized by only some patients as oppose to most or all. Twenty-one percent or less reported that most or all patients utilize any of the services. The mean of the percentage of services perceived to be utilized by most/all patients was 6% while the mean of the percentage of services perceived to be utilized by some patients was 75%.

Though the percentage was still low, oncology specific camps were perceived to be utilized by the most patients with 21% of respondents indicating that most/all patients utilize this service and 79% indicating that only some patients utilize it. This service is also perceived to be the most useful, with 100% of respondents identifying it as such. As stated, 89% of respondents identified family therapy as useful. However, a majority of participants (83%) reported that only some patients utilize this. Similarly, 83% of respondents reported that out-of-town excursions are useful, however, a majority of
respondents (83%) reported that only some patients utilize this service. These percentages showed a positive relationship between accessibility and utilization. The services perceived to be more accessible were also perceived to be utilized more.

Table 3
Accessibility and utilization of interventions

<table>
<thead>
<tr>
<th>Interventions that involve peer interaction</th>
<th>% of accessibility</th>
<th>% of utilization</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Most/all patients</td>
<td>Some patients</td>
</tr>
<tr>
<td>Support groups</td>
<td>33</td>
<td>56</td>
</tr>
<tr>
<td>Social events/ nights/ outings</td>
<td>41</td>
<td>53</td>
</tr>
<tr>
<td>Therapeutic groups</td>
<td>31</td>
<td>46</td>
</tr>
<tr>
<td>Out of town excursions</td>
<td>18</td>
<td>59</td>
</tr>
<tr>
<td>Adventure/ recreational outings</td>
<td>9</td>
<td>55</td>
</tr>
<tr>
<td>Oncology specific camps</td>
<td>74</td>
<td>26</td>
</tr>
<tr>
<td>Oncology specific online networking</td>
<td>59</td>
<td>35</td>
</tr>
<tr>
<td>Interventions that may involve peer interaction</td>
<td>25</td>
<td>58</td>
</tr>
<tr>
<td>Psycho-educational groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interventions that don’t involve peer interaction</td>
<td>53</td>
<td>37</td>
</tr>
<tr>
<td>Individual therapy</td>
<td>56</td>
<td>39</td>
</tr>
<tr>
<td>Family therapy</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Summary

Though the geographical scope of the research is small, findings from this study build upon the limited evidence supporting specific strategies for adolescent oncology psychosocial care. Discrepancies were highlighted between Northern California’s provision of psychosocial services for AOPs and the perceived usefulness and/or importance of peer interaction within these services. Moreover, a better understanding was gained of the psychosocial services being offered to AOPs in Northern California.

Nearly 90% of respondents reported that peer interaction is important to the psychosocial wellbeing of this population while only 68% reported that they believe their agencies feel the same. Interventions involving peer interaction were identified as useful by 68% or more of the respondents. However, a low percentage of these services are provided internally (mean of 18%) and a higher percentage of professionals refer patients to outside agencies for them (mean of 64%).

Furthermore, a high percentage of respondents perceive that interventions not involving peer interaction are useful and a majority of agencies provide them internally as well as refer patients to external agencies for them. Lastly, participants reported significantly higher rates of accessibility than utilization for psychosocial care. Despite the perceived usefulness of services, a majority of professionals reported that most of them are utilized by only some patients as oppose to most or all.
Chapter 5
DISCUSSION

Findings from this study build upon the limited knowledge about the usefulness of psychosocial intervention strategies for AOPs. Additionally, they contribute to the limited research on the accessibility and utilization of psychosocial services for this population. The relevance and implications of the findings from this study are discussed. Their relation to existing literature and implications for the social work profession are examined. Furthermore, speculations about the reasons for and causes behind the findings are explored and relevant recommendations are made. In conclusion, the limitations of this study are presented to help gain a better understanding of the findings and their inference.

Summary of Study

Five salient points were drawn from the results of this study, each of which are related to findings within the literature. First, nearly 90% of participants reported that peer interaction is important in the psychosocial wellbeing of AOPs, which is congruent with the consensus found in the literature (D’Agostino et al., 2011; Shama & Lucchetta, 2007; Zebrack, 2011). A lower percentage (68%) of respondents perceived that their agency views the role of peer interaction as important.

This disparity between professional and agency values potentially impacts the psychosocial care of AOPs. Much of the literature stresses the importance of establishing a healthcare environment that allows patients to interact with their support system and encourages AOPs to interact (Cassano et al., 2008; Stevens et al., 2004; Zebrack, Bleyer,
et al., 2006). Research also reveals that AOPs have difficulties finding the time and space for conventional peer interaction (Meyler et al., 2010; Mitchell et al., 2006). The value agencies place on peer interaction potentially exacerbates this difficulty by influencing hospital policies, regulations, and service provision.

Secondly, participants reported that a lack of peer interaction has the potential to affect adolescents psychologically and socially in a multitude of ways. A high majority of professionals identified that eight psychosocial variables could be affected by a lack of peer interaction for AOPs. These variables were each drawn from literature surrounding the psychosocial needs of AOPs. These findings further support previous research about this population’s psychosocial needs as well as the role of peer interaction in meeting these needs.

Third, the results of the questionnaire indicated that interventions involving peer interaction are perceived as useful by a majority of the participants. This is in congruence with previous studies that found interventions involving peer interaction to be useful and beneficial (Cassano et al., 2008; Meltzer & Rourke, 2005; Zebrack & Isaacson, 2012). In spite of this however, there is a lack of evidence-based guidelines and practices for the psychosocial care of this population (Kazak et al., 2007; Seitz et al., 2009).

Fourth, despite their perceived usefulness, a low percentage of respondents reported that their agencies provide interventions involving peer interaction internally and a high percentage reported that they refer patients to outside agencies for them. Moreover, a majority of respondents perceive interventions not involving peer interaction as useful and a majority of agencies provide these services internally as well as refer patients to
outside services for them. The researcher speculates that these findings could be influenced by financial factors. It is feasible that interventions not involving peer interaction are more easily billable through private and public insurances and that funding streams for peer-based interventions is limited.

Lastly, participants in this study reported significantly higher rates of accessibility than utilization for psychosocial services. These findings reveal a discrepancy between the usefulness of interventions and the perceived percentage of patients utilizing them. In spite of their perceived usefulness, a majority of respondents reported that most psychosocial services are utilized by only some AOPs as oppose to most or all. A majority of professionals refer patients to outside agencies for all psychosocial interventions (mean percentage of 64%) while few agencies provide interventions internally (mean percentage of 28%). Limited research exists on the utilization and accessibility of psychosocial services for AOPs. However, it has been noted that AYA’s may underutilize healthcare services as a whole in comparison to other age-group populations (Bleyer, 2005).

Furthermore, though patients are referred-out for most of the services included in this research, a high majority of professionals still perceive that only some patients utilize them. It is feasible that the low number of services provided internally contributes to the overall underutilization of them. Compounding this is the apparent gap in connection between external agencies, patients, and families. Though there is room for growth, the reported rates of accessibility are encouraging for the overall psychosocial care of this population. However, the reported rates of utilization are potentially problematic.
Implications for Social Work

With the upcoming implementation of the Affordable Care Act, it is important for social workers to be knowledgeable of its impact, goals, and values. The Affordable Care Act encourages healthcare providers to work towards integrating healthcare services. Integrated care involves the collaboration between behavioral health and physical health professionals to help care for the overall wellbeing of individuals. Integrated care takes into consideration the relationship between mental health and physical health (Substance Abuse and Mental Health Services Administration, n.d.).

Social workers have potential to play a major role in integrated care because they can represent and advocate for the behavioral, mental, and social needs of clients within the healthcare system. It is feasible that findings from studies such as this one could become increasingly valuable with this shift in healthcare. The focus on integrated care has potential to elucidate the importance of psychosocial needs and services and social workers can play a vital role in this. They can educate colleagues and the public about the importance of psychosocial care and can advocate for services that meet the needs of AOPs.

Moreover, the current focus on integrated care may have potential to expand funding sources for psychosocial services. Social workers can promote the implementation of psychosocial services they believe to be useful for AOPs such as, those that involve peer interaction. Findings from this study increase the knowledge and understanding AOPs’ unique psychosocial needs and the usefulness of specific intervention strategies. This can assist social workers and healthcare professionals in delivering appropriate care.
Furthermore, the low rates of utilization reported in this study have significant implications for social workers. Much research has shown the benefits of these services, however, there is room for substantial growth within their utilization. Social workers ecological perspective on care lends credence to their role within this. Social workers can work towards increasing the rate of utilization by exploring the reasons for the existing rates. They can follow through with referrals that are made and create innovative ways to build stronger alliances with patients, families, and outside service providers.

**Recommendations**

Appropriate recommendations were derived from the discussed findings, specifically in regards to the rates of utilization, which indicate a capacity for improvement. The researcher proposes two recommendations for achieving this. First, professionals can advocate for the provision of more services involving peer interaction internally. Findings from this study could assist them in this process, specifically within the San Francisco Bay Area and Sacramento region of Northern California. Hospitals and professionals could utilize findings from this study to support their quest for funding sources that would support providing services involving peer interaction internally. Moreover, due to the positive relationship found between accessibility and utilization, it is likely that if services are made more accessible, they will also be utilized more. The researcher acknowledges that hospital policies and billing protocols could make this difficult, leading to the researcher’s second recommendation.

It is evident that referrals being made to outside service providers are not entirely effective. High percentages of professionals are making referrals external agencies and it
is perceived that a lower percentage of patients are utilizing the external service. The researcher recommends that agencies create an environment where all parties involved in the referral process can meet. A time and space could be created for hospital staff, outside service providers, patients, and families to collaborate. This collaboration coincides well with the current shifts in healthcare philosophies and has potential to increase the rates of utilization and decrease the rates of unused referrals. Agencies, patients, and families can build stronger alliances with outside service providers, increasing the likelihood that patients will utilize them.

**Limitations**

There are three noteworthy limitations when discussing the findings of this study. First is the geographical location of the research limits the inference of its results. The geographical limits of those participating professionals challenges the sample’s representation of the statewide and nationwide population of pediatric oncology social workers and child life specialists. Therefore, the results are only representative of professionals and hospitals in the Northern California area and cannot be inferred to the statewide or national population. Secondly, the validity and reliability of the measuring instrument is limited. Because the questionnaire was self-constructed and has not been utilized prior to the experiment, its validity and reliability has yet to be established. Lastly, a snowball sampling technique was utilized, making it difficult for the researcher to assess the appropriateness of participants. The researcher was only in control of the initial distribution of the questionnaire and was not able to personally verify respondent’s profession and involvement with AOPs prior to their participation.
Conclusion

The psychosocial needs, appropriate care, and available services for adolescent oncology patients were further explored in this study. Responses to the online questionnaire yielded substantial findings. A high majority of professionals believe peer interaction is important to the psychosocial wellbeing of AOPs and a lower percentage perceives their agency feels the same. Interventions both with and without peer interaction were identified as useful. However, interventions without peer interaction are more commonly provided internally and patients are most commonly referred to outside service providers for those providing peer interaction. Rates of perceived utilization of services were much lower than perceived rates of accessibility. Cumulatively, these findings suggest that there is a gap in between the referral and utilization of these services, which are viewed as beneficial to the psychosocial wellbeing of AOPs.

This highlights the opportunity for advocacy, funding expansion, and policy change to help deliver appropriate and effective psychosocial care to this population.
Appendix A

Initial Contact Email to Prospective Participants

Hello,

My name is Christine Arneson and I am a second year Master of Social Work student at California State University, Sacramento. I am conducting research for my thesis project and it was recommended that I contact you about the possibility of participating. Your professional knowledge potentially relates to my research topic.

The purpose of this research project is to explore the psychosocial needs of adolescent oncology patients and the available services in Northern California aimed at meeting these needs. More specifically, this research aims to further explore the existence and effectiveness of psychosocial services involving peer interaction for this population. The results of this research will hopefully contribute to further developing and providing developmentally appropriate psychosocial services for adolescent oncology patients in the Northern California area.

I am looking to gather responses to an online survey from as many pediatric Social Workers and Child Life Specialists that work with adolescent oncology patients as I can. I am hoping to gather responses from various hospitals in Sacramento and the Bay Area. If this description applies to you, I would greatly appreciate your participation. If this description applies to someone you know, I would greatly appreciate if you would forward this email to him or her.

If this description applies to you:

Your professional experience and knowledge of the research topic makes your participation in this project extremely valuable and appreciated. Your participation is voluntary and you will not be compensated in any way for it. Should you choose to participate, you will be asked to complete an online questionnaire regarding your professional experience and perspectives in relation to the topic. Your participation and responses will be anonymous. In answering the questionnaire, you will represent only yourself and not your affiliated agency. To ensure your anonymity, you will not be asked to provide any identifiable information, such as your agency affiliation or personal details.

Your participation in this research would be greatly appreciated and I thank you for taking the time to consider it. If you are interested in participating, please follow the link below to my online questionnaire. You will be presented with a complete statement of consent upon following the link.
The link for my online questionnaire:

https://www.surveymonkey.com/s/adolescentoncology

The survey will be open until Friday, February 8th and I will send you a follow-up/reminder email each week until then. Please pass this email along to anyone you think might be interested between now and then. If you have any further questions regarding the research please feel free to contact me at ca2622@saclink.csus.edu. You may also contact my thesis advisor, Dr. Frances Yuen by email at fyuen@saclink.csus.edu. Regardless of your interest, thank you for your time and consideration. It is greatly appreciated.

Christine Arneson

------------------------

MSW II Student
California State University, Sacramento
Appendix B

Consent to Participate in Research

The purpose of this research project is to explore the psychosocial needs of adolescent oncology patients and the available services and interventions in Northern California aimed to meet these needs. More specifically, this research aims to further explore the existence and effectiveness of psychosocial services involving peer interaction for this population. This research is a thesis project conducted by Christine Arneson, a Master of Social Work student at California State University, Sacramento (CSUS).

You are being asked to participate in this research due to your professional experience with the target population and knowledge of the research topic. Your participation in this research is voluntary and you will not be compensated for it. You will be asked to fill-out an online questionnaire that will take approximately 15 minutes to complete. You will not be asked to provide any identifiable information, such as your agency affiliation or personal details, ensuring your anonymity.

Your responses will be kept confidential to the degree permitted by the technology used. However, no absolute guarantees can be given for the confidentiality of electronic data. You have the right to choose not to participate. Nevertheless, should you complete the survey and then choose to withdraw, I will be unable to remove any anonymous data from the database.

Your responses to the survey will be used for academic purposes only and will be accessed solely by this researcher. The data collected from this research will be properly destroyed once it has been transcribed and is no longer needed. Until then, all data will be stored securely.

If you have any questions about this research please contact Christine Arneson by phone at or by email at ca2622@saclink.csus.edu. You may also contact her thesis advisor, Dr. Francis Yuen by email at fyuen@csus.edu. This research has been reviewed according to California State University, Sacramento IRB procedures for research involving human subjects. By completing this survey, you are agreeing to participate in the research.

Click “I agree” to participate.
Appendix C

Psychosocial Needs and Services for Adolescent Oncology Patients

**Directions:** This is a study of the psychosocial needs and services for adolescent oncology patients and the role of peer-interaction within these. Each of the questions are in reference to the needs and services for adolescent oncology patients. Please answer the questions to the best of your ability. Your participation is greatly appreciated!

For the purpose of this study we will consider adolescence as being between the ages of 12-19. Additionally, the term peer interaction will be defined as:

*Reciprocal exchange between adolescent oncology patients and other adolescents who have current or past experience with cancer.*

1. Please indicate how you are involved with this population.
   - [ ] Pediatric Oncology Social Worker
   - [ ] Medical Social Worker with previous experience in pediatric oncology
   - [ ] Oncology Child Life Specialist
   - [ ] Other: __________________________

2. How important do you rate the role of peer interaction in the psychosocial wellbeing of this population?
   - [ ] Not important at all
   - [ ] Moderately important
   - [ ] Important
   - [ ] Very Important

3. How important does/did your agency rate the role of peer interaction in the psychosocial wellbeing of this population?
   - [ ] Not important at all
   - [ ] Moderately important
   - [ ] Important
   - [ ] Very Important

4. What factor(s) do you believe can cause a lack of social or peer interaction for adolescent oncology patients? (mark all that apply)
   - [ ] Hospitalization
   - [ ] Absences from school due to illness
   - [ ] Parental restrictions or fears
   - [ ] Lack of connection to old friends
   - [ ] Other: __________________________
   - [ ] Low self-esteem
   - [ ] Differences in emotional maturity
   - [ ] Differences in life experience
   - [ ] Other: __________________________
| 5. | What area(s) do you think may be affected by a lack of social or peer interaction for this population? (mark all that apply) | ☐ Self Image  
☐ Autonomy  
☐ Mental Health  
☐ Self Esteem  
☐ Confidence  
☐ Sexual/Intimate Relationships  
☐ Interpersonal Relationships  
☐ Identity Development  
☐ All of the Above  
☐ Other:______________________________  
☐ Other:______________________________ |
<table>
<thead>
<tr>
<th>Psychosocial Services</th>
<th>Do/did you provide this internally (organized &amp; facilitated by agency staff)?</th>
<th>Does/did your agency refer patients to outside services/sources for this?</th>
<th>How useful do you think this service is in addressing the psychosocial needs?</th>
<th>Does this service promote peer interaction by design?</th>
<th>Does this service effectively promote peer interaction?</th>
<th>In your opinion, what portion of patients is this service accessible for?</th>
<th>In your opinion, what portion of patients utilize this service?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support groups</strong></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Vey useful</td>
</tr>
<tr>
<td><strong>Social events/night outs/ (dances, movie nights, hospital parties, professional sporting events etc.)</strong></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Very useful</td>
<td>Useful</td>
<td>Moderately useful</td>
</tr>
<tr>
<td><strong>Therapeutic groups</strong></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Very useful</td>
<td>Useful</td>
<td>Moderately useful</td>
</tr>
<tr>
<td><strong>Out of town excursions</strong> (ex: Disneyland, New York, Mardi Gras etc.)</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Individual therapy</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Oncology specific camps</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Oncology specific online networking</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Adventure/Recreational outings (ex: ropes courses, participation in sporting events/leagues etc.)</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

- **Out of town excursions**: Whether the patient found the out of town excursions very useful, useful, somewhat useful, not useful, or if they found them sometimes useful or N/A.
- **Individual therapy**: Whether the patient found the individual therapy very useful, useful, somewhat useful, not useful, or if they found them sometimes useful or N/A.
- **Oncology specific camps**: Whether the patient found the oncology specific camps very useful, useful, somewhat useful, not useful, or if they found them sometimes useful or N/A.
- **Oncology specific online networking**: Whether the patient found the oncology specific online networking very useful, useful, somewhat useful, not useful, or if they found them sometimes useful or N/A.
### Professional & Personal Experiences Qualitative Questions

In your professional experience what types of services have you found to have the most positive effects on the psychosocial wellbeing of this population?

Are there any areas of this population’s treatment and care that you think could be improved within your agency? If so, how?
Appendix D

Human Subjects Application Approval

CALIFORNIA STATE UNIVERSITY, SACRAMENTO
DIVISION OF SOCIAL WORK

To: Christine Arneson                Date:  11/1/2012

From: Committee for the Protection of Human Subjects

RE: YOUR RECENT HUMAN SUBJECTS APPLICATION

We are writing on behalf of the Committee for the Protection of Human Subjects from the Division of Social Work. Your proposed study, “A psychosocial Needs and Services Assessment for Adolescent Oncology Patients.”

___X___ approved as ___ X ___ EXEMPT  ___ MINIMAL RISK ___

Your human subjects approval number is:  12-13-034. Please use this number in all official correspondence and written materials relative to your study. Your approval expires one year from this date. Approval carries with it that you will inform the Committee promptly should an adverse reaction occur, and that you will make no modification in the protocol without prior approval of the Committee.

The committee wishes you the best in your research.

Professors: Maria Dinis, Jude Antonyappan, Teiahsha Bankhead, Serge Lee, Kisun Nam, Maura O’Keefe, Dale Russell, Francis Yuen

Cc: Yuen
References


SurveyMonkey. (2012). What is the enhanced security option (SSL encryption)? Retrieved from


http://www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood


