IDENTITY AND OPTIMISM IN ADOLESCENTS WITH CANCER: A VISUAL PERSPECTIVE
Clendening Summer Fellowship Proposal
Errin Mitchell

Introduction:

Cancer during adolescence is a life-changing event for both the adolescent and their family. Normally, adolescence is a time for movement towards independence and acquiring skills to carry out adult relationships, and it is critical time for development of a positive self-identity. However, the effects of cancer may make some of these developmental tasks more difficult to achieve. This project aims to explore the narratives of adolescents with cancer in an effort to understand how cancer impacts the development of an adolescent’s self-identity. When examining the development of self-identity, both self-concept and self-esteem must be considered. Because research has shown that the development of self-esteem can impact optimism in adolescents (Puskar et al., 2010), this project will examine how the development of identity in adolescents impacts their optimism levels. Finally, elements of photovoice will be used in order to gain a novel and unique perspective from the adolescents. Cancer during adolescence is filled with complex challenges and changes; and this study would allow for an invaluable new perspective that would lead to increased understanding and appreciation for the intricacies of adolescent cancer.

Background:

Adolescents with cancer face unique challenges, as they are undergoing diagnosis and treatment in addition to the developmental adjustments and difficulties inherent in their life-stage (Li, Lopez, Joyce Chung, Ho, & Chiu, 2013). Day-to-day routines, relationships, major milestones, and self-esteem are all threatened by cancer (R. L. Woodgate, 2005). Previous research has found that although having cancer does not necessarily lead to difficulties in adjusting and developing, it does put adolescents at increased risk for psychosocial problems (Gregurek, Bras, Dordević, Ratković, & Brajković, 2010). There has been increased attention to the influence cancer can have on an adolescent’s sense of self since adolescence is a critical period for the development of a positive self-identity. Past research has suggested that cancer universally changes the way adolescent survivors view themselves, and that change can be both positive and negative (Anholt, Fritz, & Keener, 1993; Smith, Ostroff, Tan, & Lesko, 1991; Zebrack & Chesler, 2001). Other research has found that children and adolescents with cancer experience a negative impact on their self-concept due to their illness and its treatment. However, much less research has been done looking at the narratives told by the adolescents themselves. Furthermore, it is important to consider how the development of self-esteem will impact optimism. Self-esteem specifically refers to the negative or positive value ascribed to the self-concept (R. Woodgate & McClement, 1997). If cancer impacts the development of self-esteem in adolescents, it is important to understand optimism in adolescents with a serious illness, such as cancer, given that optimism is known to be an important predictor of health outcomes (Hinds, 1988).
**Personal Motivation:**

When I tell people I am interested in pursuing a career in pediatric hematology/oncology, I often get a response of, “Ooh, that would be a really sad job.” This response is often disconcerting to me because I have never seen it that way. Sure, the idea of sick children is not exactly happy, and there is a morose quality to any job that involves death, but that is part of being a doctor. I find that working with this population can be incredibly gratifying. There is a resilience often found in youth that is much more rare in adults. For them, the world is still a magical place with discoveries to be made and adventures to be had, which is remarkable to see in the face of such great adversity. This is why I have continuously been drawn to pediatric hematology/oncology (beyond just being fascinated by the pathology of these diseases).

During college, I focused my studies on health psychology. I was intrigued by the complex interactions between the mind and the body and how delicately intertwined the two are. I quickly became involved in research area, eventually writing my honors thesis on how genetic polymorphisms relate to stress reactivity. This project would be an ideal opportunity to pursue psychosocial research as a medical student and a wonderful chance to combine my interests in psychology and pediatric oncology.

I was drawn to this specific project after spending a year working with adolescents from an underserved background. I have been able to see how adversity can impact an adolescent’s capacity to figure out who they are and how they feel about their identity. Given my interest in pediatric oncology, I have become very interested in the psychosocial impacts cancer can have on adolescence. Furthermore, I want to use photovoice as a way to give participants control. This is a population that can often feel powerless to their illness, and I would love to see the results of giving them the control to image their world. Given the psychosocial complexities associated with adolescents with cancer, this study would allow for new insight into a nearly unimaginable way of being.

**Description:**

<table>
<thead>
<tr>
<th>Specific Aims</th>
<th>Methods</th>
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<tbody>
<tr>
<td>1. To investigate the narratives of adolescents with cancer, specifically their development of identity</td>
<td>1. Use photovoice to guide the narratives and elicit a new perspective</td>
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<td>2. To assess their levels of optimism and how that relates to the development of identity</td>
<td>2. Conduct semi-structured interviews of adolescent cancer patients</td>
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My project intends to examine the following questions:

1. How do adolescents with cancer develop their identity?
2. In what ways does having cancer impact the development of an adolescent’s identity?
3. Does the impact on the development of identity affect optimism in the adolescents?

Specifically, this project intends to:
• Use photovoice to elicit adolescent perspectives
• Explore the narratives of adolescents with cancer to better understand their perspective
• Examine the self-identity amongst adolescents with cancer
• Measure the levels of optimism in adolescents with cancer at a single time point
• Identify any common themes and patterns in the development of identity amongst adolescents with cancer

As a secondary aim, this project intends to begin to understand how the levels of optimism relate to the development of self-concept.

For my project, I plan to use photovoice as a part of the data collection. Photovoice is an exploratory research method that helps to give insight into how a population conceptualizes their situation using images (C. C. Wang, Yi, Tao, & Carovano, 1998). Typically in photovoice, groups of people are given cameras to record their reality and engage with researchers to foster understanding and advance change (C. Wang & Burris, 1997). Previous photovoice studies have shown that this method can be valuable in capturing aspects of life that traditional surveys cannot (Catalani & Minkler, 2010). Using this tool in my study will allow me to gain information personalized to the individual participants that would be difficult to obtain solely with traditional research methods.

Timeline:

March/April: Develop/Finalize set of interview questions and submit for IRB approval.
May: Begin recruiting participants at Children’s Mercy Hospital upon approval of the IRB. At time of recruitment, participants will be consented and given cameras and instructions. Their interview will be scheduled during the 8-week project timeline.

Methods:

For this project, I have been in contact Joy Fulbright, MD, and Kristin Stegenga, PhD, RN, who have agreed to mentor me. Dr. Fulbright is a pediatric hematologist oncologist at Children’s Mercy Hospital who specializes in the clinical treatment of adolescents and young adults with cancer. Kristin Stegenga is a research nurse at Children’s Mercy in the Division of Hematology/Oncology/Bone Marrow Transplantation. Her research experience primarily lies in studying the narratives and quality of life in adolescents with cancer and sickle cell disease. She also has experience with using photovoice with adolescents. Both are enthusiastic about this project and have been instrumental in the development of the project thus far.

This project will focus on patients between the ages of 12-18. Patients must have current cancer diagnosis that was received at least 6 months prior to recruitment. This is to ensure that they have had time to process their diagnosis and how it relates to their self-identity. My goal is to have at least 10 participants complete the study by the end of the
I will be recruiting patients from Children’s Mercy Hospital in Kansas City. Patients who come in for a scheduled visit will be given details of the study in age-appropriate terms and asked to participate. Those who consent will be given cameras to take photos and scheduled for an interview during their next hospital visit. If their next visit is after the end of July, arrangements can be made to schedule an earlier interview. Patients will also be asked for email and phone number, and I will confirm if it is ok to text/email them reminders. I will also use their email address to send them an invite to Dropbox to upload their photos prior to their next interview. As an incentive to completing the study, patients will be allowed to keep the camera after the study is over. At the time of consent, participants will receive instructions on how to use the cameras. They will also be encouraged to take photos that represent who they are and their life with cancer. If they take photos of others, they will need to obtain a signed photo release from that person or their parent (if they are under 18). I will later email them text instructions for using Dropbox to upload their photos if they are able. I will email or text them a reminder once a week about taking or uploading the photos. Participants will also be asked to bring the camera to the interview in case they forget or are unable to upload the photos. I will send a text or email the day before the interview to remind them to bring the camera and photo releases.

At their next appointment, patients will participate in a semi-structured interview, with the photos used as a way to guide the interview. Participants will be asked questions about how they view themselves, their attitudes towards themselves, the qualities they attribute to themselves, and the value they place on their attributes. Photos taken prior to the interview will be used to guide their answers and elicit a visual perspective on their identity. Each photo will be assigned a number to which it will be referred throughout the interview in order to insure that later, during analysis, I will be able to know what photo they are sharing information about. For each photo, I will ask participants to tell me about the photo, which further prompts such as “How does this represent you or your life?” if necessary. The interview will consist of open-ended questions. Examples of questions that might be asked include:

- Some kids with cancer have told me that having cancer makes their day-to-day lives different. What has it been like for you? How does this photo represent your day-to-day life?
- What were you feeling when you took this photo? Do you feel that way frequently? Has having cancer changed the way you feel?
- Do you think cancer has changed you? If so, in what ways?
- What do you feel are your positive qualities? What things would you want to change about yourself?
- What are some things in the future you’re looking forward to?

At the end of the interview, participants will fill out demographic information, as well as a survey measuring optimism. To measure optimism, I plan to use the Life Orientation Test-Revised (Scheier, Carver, & Bridges, 1994). Each interview will last approximately 30-60 minutes or as long as it takes to discuss all the participants photos. Afterwards, interviews will be transcribed using a professional transcription service. I will then use qualitative content analysis to analyze the data. This will be done by coding the text to identify patterns and themes. When analyzing the interviews, special attention will be paid to
themes of optimism and self-esteem. Then, the data will be further analyzed for correlations between patterns of optimism in individual participant’s photos and narratives and the measured levels of optimism.

Budget:

<table>
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<tr>
<th>Description</th>
<th>Cost</th>
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<tbody>
<tr>
<td>Cameras – 15 cameras at $59.99 each + Tax (See Appendix)</td>
<td>$978.75</td>
</tr>
<tr>
<td>Transcription Services – $1/min*</td>
<td>$1,000.00</td>
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<tr>
<td>Living Expenses (Mostly consists of food/groceries)</td>
<td>$500.00</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>$2,478.75</strong></td>
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Should my actual expenses surpass that of my estimated budget, I understand that I am responsible for any expense exceeding the $2,500 stipend.

*Note: I am budgeting for each interview to take at least 60 minutes, plus some room for participants to talk more.

Mentors:

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Kristin Stegenga, RN, PhD
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Bibliography


Canon PowerShot A2500 16MP Digital Camera with 2.7-Inch LCD (Red)

by Canon

4.5 out of 5 stars 606 customer reviews

216 answered questions

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Details

Color: Red

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- 5x optical zoom and 28mm wide-angle lens with Digital Image Stabilizer
- Smart Auto intelligently selects the proper settings based on 32 predefined shooting situations
- USB cable not included