DISCLOSURE EXPERIENCES OF CANCER SURVIVORS

WHO ARE IN COLLEGE

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DEDICATION

This thesis is dedicated to Diane Frances Pan and Sandra Louise Milburn.
ABSTRACT OF THE THESIS

Disclosure Experiences of Cancer Survivors Who are in College
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Master of Arts in Psychology
San Diego State University, 2013

As a result of major advancements in treatment, an unprecedented number of children are surviving cancer and living well into adulthood. Long-term survival, however, brings unique psychosocial issues, such as cancer survivors’ decision to disclose their cancer history with others. The aim of this study was to take a qualitative approach to explore the disclosure decisions and experiences of cancer survivors who are in college. Since disclosure of a personal history with cancer is an unexplored topic among college students, we sought to gather descriptive information about disclosure and important related constructs, such as identity development and belongingness. Study participants were recruited through a California-based cancer survivor scholarship program and by a nation-wide distribution of a study flyer to cancer- and college-related venues, list-serves, websites, and social media. Twelve undergraduate college students with a personal history of cancer, age 18 – 30 years, took part in a one-on-one, semi-structured interview conducted via video chat. The sample consisted of five men and seven women. The amount of time elapsed between cancer diagnosis and study interview ranged from 6 months to 20 years. Most of the participants had a type of leukemia or lymphoma. Other cancers were brain cancer, carcinoma of the tongue, dysgerminoma, and endodermal sinus tumor. The average duration of the interviews was 77 minutes. Participants were asked open-ended questions concerning their decision to disclose and perceptions of others' reactions to their disclosure around the time of their diagnosis, during treatment, post-treatment survivorship, return to K-12 grade schooling, and college. Participants were also asked questions about changes to physical appearance, late effects due to their cancer treatment, adjustment to college, cancer-survivor identity, and relationships with peers. The data were organized and analyzed using Dedoose, Version 4.5 Web Application for Managing, Analyzing, and Presenting Qualitative and Mixed Method Data. Guided by Consensual Qualitative Research recommendations, recurrent themes and categories were identified using inductive, data-driven analysis. Due to the great diversity of personal experiences, information saturation has yet to be reached for all topics. Four domains were identified: (1) voluntary disclosure across time (i.e., diagnosis, treatment, post-treatment survivorship, return to K-12 schooling, and college), (2) cancer-survivor-related identity development, (3) belongingness and connecting to peers, and (4) advice to other young cancer survivors about disclosure. Future directions include recruiting more participants in an effort to reach information saturation and to revisit data analysis. Preliminary findings suggest several testable hypotheses for future research. Final findings will have the potential to inform the development of a needed measure of cancer-related disclosure and will provide insights for targeted intervention development.
TABLE OF CONTENTS

ABSTRACT ..................................................................................................................v
LIST OF TABLES ......................................................................................................... vii
LIST OF FIGURES ....................................................................................................... ix
ACKNOWLEDGEMENTS ........................................................................................ x
CHAPTER
1 INTRODUCTION ........................................................................................................1
   Pediatric Cancer .......................................................................................................1
   Disclosure ..................................................................................................................2
   Cancer Survivor Identity .........................................................................................2
   Cancer and Stigma ..................................................................................................4
   Cancer and Disclosure ............................................................................................5
   Cancer, College, and Disclosure ............................................................................9
   The Present Study ....................................................................................................10
2 METHOD ..................................................................................................................12
   Participants .............................................................................................................12
   Procedure ................................................................................................................12
   Measures ................................................................................................................14
   Data Analysis ..........................................................................................................15
3 RESULTS ................................................................................................................16
   Disclosure in College: Comfort and Openness .....................................................16
   Disclosure in College: To Whom ...........................................................................17
   Disclosure in College: Why and Why Not ...........................................................20
   Disclosure in College: Others’ Responses to Disclosure and Participants’ Feelings about Others’ Responses .................................................................22
   Pre-college Disclosure Experiences .....................................................................24
   Exceptional Support During Diagnosis and Treatment .......................................25
   Relationships with or Awareness of Other Pediatric Cancer Survivors or Children with Other Chronic Health Conditions ...................................................27
Physical Changes and Long-term Effects ................................................................. 28
Cancer Survivor Identity ......................................................................................... 30
Belongingness and Connecting to Peers ................................................................. 32
Advice to Other Young Cancer Survivors about Disclosure ................................. 34

4 DISCUSSION ........................................................................................................... 36
  General Discussion ................................................................................................... 36
  Limitations and Future Directions ........................................................................ 39

REFERENCES .............................................................................................................. 41

APPENDICES
  A RECRUITMENT FLYER ......................................................................................... 46
  B RECRUITMENT E-MAIL ....................................................................................... 48
  C CONSENT DOCUMENT ....................................................................................... 50
  D INTERVIEW PROTOCOL ..................................................................................... 54
  E RESOURCE LIST .................................................................................................. 61
LIST OF TABLES

PAGE

Table 1. Participant Characteristics ......................................................13
LIST OF FIGURES

Figure 1. Participants’ level of and comfort with disclosure in college. .................................. 18
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CHAPTER 1

INTRODUCTION

PEDIATRIC CANCER

Due to major advancements in treatment, more children treated for cancer are now surviving into adulthood (American Cancer Society [ACS], 2011). The five-year survival rate for pediatric cancer survivors (diagnosed under the age of 20 years) reached 80%, as of 2001 (Howlader et al., 2012), and as of 2005, an estimated 328,652 pediatric cancer survivors were alive in the United States (Mariotto et al., 2009). Childhood (ages 0 to 14 years) and adolescent (ages 15 to 19 years) cancers are rare, representing 1.1% of all cancer incidences (Howlader et al., 2012), but are the second leading cause of mortality among children (ACS, 2012b) and the fourth leading cause of mortality among adolescents (Howlader et al., 2012).

Some of the most common types of cancers that occur in children are neuroblastoma, Wilms tumor, rhabdomyosarcoma, and retinoblastoma (ACS, 2011). Leukemia, lymphoma, and brain cancer are common types of cancers in both children and adolescents (ACS, 2011; Bleyer, Budd, & Montello, 2006). Depending on the type and stage of the cancer, different forms of treatment may be used, such as chemotherapy, surgery, radiation therapy, and/or other types of treatment (ACS, 2011). These treatments often cause severe side effects during treatment (e.g., weight loss or gain, swelling, nausea, vomiting, itchiness, pain, headaches) and late effects months to years after treatment is completed (e.g., slowed or decreased growth and development, coronary or pulmonary problems, learning deficits, decreased cognitive functioning, infertility, secondary cancers; ACS, 2012a). Additionally, a cancer diagnosis and the subsequent treatment experience during childhood or adolescence can potentially disrupt social development, emotional health, and academic progress (Gurney et al., 2009). Psychosocial difficulties are not limited to the acute treatment phase and may reverberate discontinuously throughout the life of the survivor (Gurney et al., 2009). Post-treatment cancer survivorship is an area of growing interest in both treatment and research settings. Given the high survival rates associated with pediatric cancers and the indication
that many pediatric cancer survivors will experience long-term and late effects, it is important to better understand these survivors’ experiences in an effort to improve their overall quality of life (Eilertsen, Jozefiak, Rannestad, Indredavik, & Vik, 2012).

Moreover, cancer treatments may alter cancer survivors’ physical appearances (Larouche & Chin-Peuckert, 2006). These changes may be temporary (e.g., swelling and hair-loss due to chemotherapy) or permanent (e.g., scarring, limb-loss, skin discoloration, and hair-loss due to radiation; ACS, 2012a). Changes to appearance can impact cancer survivors’ body image and social interactions, which may be particularly true and important for adolescent cancer survivors (Larouche & Chin-Peuckert, 2006). In addition, the extent to which a person’s experience with cancer is visible or concealable is defined by changes to appearance. Thus, survivors with limited or no physical changes to appearance must make decisions about sharing their cancer experience with others (Green et al., 2012), while survivors with obvious appearance changes may feel exposed and that their cancer experience is public information (Larouche & Chin-Peuckert, 2006).

**DISCLOSURE**

Self-disclosure (i.e., sharing personal information with others through verbal communication; see Slone, 2010, for a review) and written disclosure (i.e., expressing personal feelings through writing; see Sexton & Pennebaker, 2009, for a review) provide an opportunity to express thoughts and feelings and to develop a sense of self. Both forms of disclosure have been associated with mental and physical health benefits in a wide variety of populations (Smyth, Pennebaker, & Arigo, 2012). Two subtypes of disclosure have been studied in cancer survivors: (1) diagnosis and treatment/identity disclosure (e.g., ‘I had cancer’ or ‘I am cancer survivor’), and (2) emotional/insightful disclosure (e.g., ‘My experience with cancer has made me a better person,’ ‘I don’t think I’ll ever feel like myself again,’ or ‘I feel lonely and sad’). The current study is primarily interested in the former, which serves as a prerequisite for the latter.

**CANCER SURVIVOR IDENTITY**

Cancer survivorship may result in identity reconstruction (Park, Bharadwaj, & Blank, 2011) and “the integration of a new and perhaps permanent identity” (Zebrack, 2001, p. 238).
Indeed, a small body of research suggests that people who have been diagnosed and treated for cancer have integrated their cancer experience into their self-concept (Song et al., 2012). Yet, research on cancer survivor identity is limited, and among people who have experienced cancer, adopting the label “cancer survivor” varies widely. For instance, Bellizzi and Blank (2007) asked a sample of 490 men with prostate cancer, “When you think about yourself in relation to your prostate cancer, which adjective or phrase best describes you: a patient, a victim, someone who has had prostate cancer, cancer survivor, or cancer conqueror?” (p. 45).

In this sample, only 26% of the men self-identified as a “cancer survivor”; most men identified as “someone who has had prostate cancer” (Bellizzi & Blank, 2007). In contrast, when asked the same question with the option to rate each label on a scale from 1 (“not at all”) to 5 (“very much”), 83% of 168 young to middle-aged people with various types of cancer endorsed “cancer survivor” at least somewhat; 81% of the sample endorsed “person who has had cancer” at least somewhat, making it the second most popular label (Park, Zlateva, & Blank, 2009). Furthermore, in a sample of people over the age of 60 years who were diagnosed with cancer at least five years prior to participating in the study, almost 90% identified as a “cancer survivor” (versus “victim” or “patient”; Deimling, Bowman, & Wagner, 2007). Across all three of these studies, findings suggest that identifying as a “survivor” can positively influence mood and well-being (Bellizzi & Blank, 2007; Deimling et al., 2007; Park et al., 2009). How one identifies in relation to their cancer experience may be associated with cancer-related disclosure experiences. Specifically, a person who integrates their cancer experience into their self-concept and has negative perceptions of cancer may feel a greater dilemma about cancer-related disclosure (Park et al., 2011).

Conversely, a person who integrates their cancer experience into their self-concept and has positive perceptions of cancer may feel less of a dilemma or no dilemma about cancer-related disclosure.

In addition, an experience with cancer may have a greater impact on children and adolescents who are still in the process of developing their self-concept and identity (Song et al., 2012). In a qualitative study with 12 post-treatment adolescent cancer survivors, Jones, Parker-Raley, and Barczyk (2011) found that adolescent cancer survivors emphasized differences between themselves and their healthy peers, such as changes to appearance, physical limitations, and how protective their parents were of them as compared to siblings.
or to the parents of healthy peers. These prominent differences acted as constant reminders of their cancer diagnosis and treatment effects, and possibly served to establish and reinforce their cancer survivor identity. Additionally, survivors further displayed evidence of forming a survivor identity through an openness to talk to and educate people about their cancer experiences. Survivors, however, expressed discomfort when telling people that they had cancer because of a sense that other people were not open to the survivors’ discussion of their cancer experiences. Yet, survivors still felt a need to tell new friends about their cancer diagnosis and treatment in the interest of honesty and in anticipation of their cancer history inevitably coming up (Jones et al., 2011).

**Cancer and Stigma**

Disclosure has been extensively studied in individuals who harbor a concealable stigma (i.e., an attribute that is viewed as reducing someone from a whole person to a discounted one; Goffman, 1963), and has been linked to a wide variety of psychological, health, and behavioral outcomes (see Chaudoir & Fisher, 2010, for a review). For example, in a recent study considering the disclosure experiences of Danish HIV-positive women and men, Rodkjær, Sodemann, Ostergaard, and Lomborg (2011) identified a continuum of three strategies: disclosure to everyone (being open), restricted disclosure (being partly open), and disclosure to no one (being closed). Each strategy implied a range of benefits and detriments related to secrecy, control, social support (vs. isolation), and stigma and prejudice. No single strategy stood out as more beneficial or harmful than the others (Rodkjær et al., 2011). Disclosure decisions were based both on individual and social factors and were not limited to the time of diagnosis, but recurred as a challenge throughout the person’s life.

There are several differences between HIV/AIDS and cancer. Not disclosing a diagnosis of HIV/AIDS can result in serious consequences (e.g., transmission), whereas cancer is not contagious or transmittable. Cancer is described in the literature as having a less negative association than HIV/AIDS (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Green & Banerjee, 2006). Yet, it is likely that cancer survivors face similar decisions and stressors in relation to disclosure. Unlike HIV/AIDS, people diagnosed with cancer can potentially be cured (ACS, 2012a). However, some cancers cannot be cured and become chronic illnesses (ACS, 2012a). Furthermore, physical and/or cognitive limitations induced
by treatment may cause ongoing problems for cancer survivors. Although perceptions of
cancer are not typically negative, the disease still holds the potential to be stigmatizing
(Knapp-Oliver & Moyer, 2009). Research has shown that people hold both positive and
negative stereotypes regarding survivors (Song et al., 2012). Examples of negative
stereotypes include having low cognitive competence and sociability; positive stereotypes
include being strong and determined (as cited in Song et al., 2012). Additionally, cancer
patients have reported that people treat them differently, either by avoiding them or by being
overly attentive (Gray et al., 2000). For people with HIV/AIDS, stigma was found to be the
main barrier to disclosure (Rodkjæer et al., 2011). Perceived stigma has also been reported as
a primary deterrent to disclosure in studies with cancer survivors (Gray et al., 2000; Hilton,
Emslie, Hunt, Chapple, & Ziebland, 2009). Thus, if cancer survivors perceive cancer to be a
stigmatized identity, then cancer survivors may face similarly complex decision-making
challenges regarding disclosure as people with HIV/AIDS.

CANCER AND DISCLOSURE

Studies on self-disclosure among cancer survivors have primarily focused on breast
cancer survivors (Figueiredo, Fries, & Ingram, 2004; Henderson, Davidson, Pennebaker,
Gatchel, & Baum, 2002; Low, Stanton, & Danoff-Burg, 2006; Pasipanodya et al., 2012;
Pistrang & Barker, 1992; Shim, Cappella, & Han, 2011). The studies on breast cancer
patients have predominantly investigated barriers to disclosure (i.e., social constraints;
Pasipanodya et al., 2012), written emotional disclosure (see Stanton & Danoff-Burg, 2002,
for a review), and negative and positive word valence as predictors of health outcomes (Low
et al., 2006; Shim et al., 2011). Pasipanodya et al. (2012) used an electronic daily-diary
methodology to examine the influence of social constraints on individual and relationship
well-being in a sample of couples coping with the recent diagnosis and treatment of early-
stage breast cancer. Social constraints were defined as the extent to which the patient
perceived that her spouse avoided, rebuffed, or appeared disinterested in the patient’s attempt
to share or discuss her cancer-related concerns. Social constraints were related to decreased
sharing of the best and worst events of the day and reduced likelihood of sharing the worst
event of the day when it was cancer-related. Social constraints were also related to lower
levels of self-esteem and relationship well-being (i.e., intimacy and relationship happiness).
Using baseline survey data and an analysis of four months of messages posted to online support groups, Shim et al. (2011) found that disclosure of insights led to greater improvements in health self-efficacy, emotional well-being, and functional well-being. Disclosure of negative emotions was unrelated to health outcomes. In contrast, Low et al. (2006) found that greater use of negative emotion words in essays predicted reduced physical symptoms.

Few studies have examined the reasons a cancer survivor might choose to disclose or conceal their cancer history. In a quantitative study with breast cancer survivors, greater cancer-related disclosure was predicted by younger age, greater disease severity, greater optimism, and greater stress-related growth (Henderson et al., 2002). In a sample of prostate cancer survivors who were two to three years post-treatment, Jackson et al. (2010) found that the need for social support and the opinion that others had a ‘right to know’ were men’s primary reasons for disclosing their diagnosis and treatment. In contrast, in a longitudinal, qualitative study conducted with prostate cancer patients pre-surgery, 8 – 10 weeks post-surgery, and 11 – 13 months post-surgery, Gray et al. (2000) found that men largely avoided disclosing information about their illness in an effort to sustain a normal life. Other factors related to men’s decisions to limit disclosure included fear of stigmatization, practical necessities at work, and the desire to avoid burdening others (Gray et al., 2000). The variance in participants’ place on the cancer continuum and in the years when these two studies were conducted (i.e., 2007 – 2008 vs. 1997 – 1999, respectively) could account for the discrepant results. Further research is needed to examine why men and women survivors of various cancers and with varying experiences disclose their cancer history.

Among cancer survivors, past studies have investigated outcomes linked to disclosure. In a quantitative study, Figueiredo et al. (2004) asked 66 early-stage breast cancer patients to rate their level of concern about six different dimensions of breast cancer (e.g., physical problems, uncertainty of recurrence) and to rate their level of disclosure about each of the six concerns (i.e., “talked about none of what I felt” to “talked about all of what I felt”). Participants who reported lower disclosure also reported lower emotional well-being, less social support, and more unsupportive social interactions. In a sample of prostate cancer survivors, men reported that they felt positive emotions (i.e., relief and reduced worries) after sharing their diagnoses with others (Jackson et al., 2010). In contrast, some men reported that
they did not have any worries to be affected by a disclosure experience (Jackson et al., 2010). The study did not specify the types of worries to which the participants were referring. Although disclosure has been studied extensively in breast cancer survivors and prostate cancer survivors, to date, the author was only able to locate two studies (i.e., Hilton et al., 2009; Park et al., 2011) that examined the disclosure experiences of young cancer survivors and one study in which disclosure was an unexpected outcome (Thompson, Long, & Marsland, 2013).

Hilton et al. (2009) conducted narrative interviews with 37 survivors who were 18 to 34 years of age at the time of their diagnosis. The aim of the study was to understand how young adults disclosed their cancer diagnosis to family and friends and to determine the similarities or differences between the disclosure behaviors of men and women (Hilton et al., 2009). Both men and women found it difficult to tell their friends and family about their diagnosis because of the sorrow it caused their loved ones and the subsequent guilt the survivors felt for causing this distress. Similarly, survivors expressed a desire to be “strong for everybody else” by remaining upbeat, in a good mood, and concealing any negative emotions. Despite the difficulty of sharing their diagnosis with friends and family members, most participants reported being open about their illness and having disclosed to family, friends, and close coworkers. A small number of participants, who were mostly men under 25 years of age when diagnosed, reported being more secretive about their diagnosis because of concerns about being excluded from groups of friends, fears of being treated differently by peers or stigmatized, and living up to perceived gender expectations. Most of the younger survivors in the study were accompanied by their parents during their diagnosis and noted being dependent on their parents for support while their peers were in the process of establishing their independence. Younger survivors, relative to survivors over 25 years old, were more concerned about the reactions from their friends and colleagues than from their family members. They struggled against their identity as a cancer patient to maintain their identity as a young person. Younger participants in this study faced unique difficulties, and as a result, were particularly selective about disclosing their diagnosis. This study, however, was conducted in the United Kingdom where perceptions of cancer might be different from those in the United States. Furthermore, since participants in this study had been diagnosed zero to five years prior to the interview, they were only asked to provide retrospective
information about their thoughts, feelings, and experiences regarding their disclosure decisions around the time of their diagnosis. No information was provided about long-term survivorship disclosure decisions.

Park et al. (2011) were interested in the association between illness centrality and well-being among young to middle-aged cancer survivors and whether disclosure/openness moderated this relationship. Illness centrality is the “extent to which one’s core self is now situated in the context of cancer, that is, the centrality of the cancer to one’s identity” (Park et al., 2011, p. 881). Disclosure/openness was conceptualized as participation in eight common cancer-related activities (i.e., “belong to cancer-related organizations,” “contribute money to cancer-related causes,” “participate in cancer-related activities [e.g., walk for research],” “participate in cancer-related advocacy to public officials,” “follow media stories related to cancer treatment or survivorship,” “wear cancer-related items, such as bracelets, t-shirts,” “talk about your own experience with family, friends, coworkers, and so on,” and “talk about prevention or screening value to family, friends, coworkers, and so on”). Participants were asked to circle all that applied, and responses were coded dichotomously (i.e., “yes” or “no”). Disclosure/openness was predictive of more positive affect and post-traumatic growth, but it did not moderate the relationship between illness centrality and well-being. The authors noted that their measure might have been a potentially problematic measure of disclosure and an inadequate reflection of the broader construct of disclosure. The authors recognized that future research should adequately inquire directly about the comfort level and status of disclosure of one’s cancer experience.

Self-disclosure has been noted as a concern in the context of young cancer survivors and romantic relationships (Hamilton & Zebrack, 2011; Thompson et al., 2013). In a study focused on the impact of having cancer as a child on romantic relationships during young adulthood, Thompson et al. (2013) found disclosure of cancer history and disclosure of personal thoughts and emotions to be major concerns of female cancer survivors, ages 18 – 25 years. Survivors found cancer-related communication difficult because of concerns about people’s reactions, the fear of experiencing strong emotions related to their cancer experience, and the desire to not appear vulnerable as a result of their cancer experience (Thompson et al., 2013). With regard to cancer and dating, patient education materials offer a plethora of seemingly sound advice to cancer patients about dating and disclosure. Although,
as Hamilton and Zebrack (2011) have noted, the utility of the suggestions offered by the patient education materials has yet to be tested empirically. Future research on dating and disclosure is necessary, because cancer survivors have noted this as an area of concern, and research has shown that survivors have significantly higher rates of never getting married than their siblings and US Census data (Janson et al., 2009), despite having a high interest in being in a relationship (95% of those under 50 years of age; as cited in Hamilton & Zebrack, 2011).

**Cancer, College, and Disclosure**

No known studies have considered the disclosure experiences of pediatric cancer survivors who are in college, a critical period for identity development and social connectedness (Schwartz, Donnellan, Ravert, Luyckx, & Zamboanga, 2013). In the general population, adjustment to college is seen as a difficult time. College students have to navigate a new social environment and manage separation from friends and family (Crede & Niehorster, 2012). This separation and adjustment process may be particularly difficult for cancer survivors, as they deal with possible late effects of their cancer treatment and the added pressure of denying or integrating their cancer survivor identity. Moreover, college might be the first time that young cancer survivors have to make the decision to disclose or conceal their cancer history. During active treatment before college, children and adolescents may not be able to conceal their illness because of the often-disruptive nature of the cancer diagnosis and subsequent treatment (e.g., missed school and aforementioned side effects). Parents may need to communicate with their child’s school to request accommodations and/or home schooling during active treatment. A representative from the hospital where the child or adolescent is being treated may even visit the child’s or adolescent’s school to assist with answering questions from classmates (e.g., the Children’s Hospital Los Angeles School Transition and Re-entry Program). Thus, the cancer survivor’s social network (e.g., family, friends, classmates, teammates, teachers, administrators) will likely be aware of their cancer experience. Furthermore, it is reasonable to assume that survivors will have the same peer group throughout their kindergarten to 12th grade education. Thus, college may be the first time that survivors of pediatric cancers have needed to actively make disclosure decisions.
Disclosing a concealable, stigmatized identity for the first time is a complex process, and its effects can last long afterwards (Chaudoir & Quinn, 2010).

It is unclear whether disclosure will be beneficial, harmful, or neutral for cancer survivors who are in college. On the one hand, disclosure is viewed as a necessary prerequisite for social support (Chaudoir & Fisher, 2010); specifically, it is difficult to provide social support for an issue of which one is unaware. Social support plays an important role in adjustment to cancer (Jackson et al., 2010) and to college (Nicpon et al., 2006). Indeed, social connectedness in academic settings has been shown to predict favorable mental and physical health outcomes (Walton & Cohen, 2007), as well as academic persistence (Nicpon et al., 2006). Moreover, adolescent and adult cancer survivors have noted a decrease in social support after completing treatment (Jones et al., 2011; Stovall, 2005). Thus, disclosure in college might lead to an increase in cancer-related social support and improved academic outcomes for survivors. However, these benefits might not be realized. Instead, disclosing their cancer survivor status might yield feelings of exclusion and disconnectedness from their peers. This will likely depend on two major factors: (1) the extent the student identifies as a cancer survivor, perceives negative stereotypes about cancer survivors, and believes that a cancer survivor identity is a devalued identity; and (2) the reaction of the person with whom the survivor chooses to confide (Chaudoir & Fisher, 2010). Recent research suggests that the reaction of the person with whom the survivor chooses to confide is one of the most important factors predicting whether disclosure will be harmful or beneficial (Chaudoir & Fisher, 2010; Lepore & Revenson, 2007). Furthermore, cancer survivors who completed treatment as children, many years prior to college, might not identity as a cancer survivor anymore (Park et al., 2011) or feel the need for social support related to their cancer experience. For these survivors, deciding whether or not to disclose their cancer history might not be a stressful process.

**The Present Study**

The current study explored the disclosure experiences of cancer survivors who are in college and is significant for the following reasons: (1) adolescence, including the college years, is a period of increased psychosocial difficulties (Crede & Niehorster, 2012; Pendley, Dahlquist, & Dreyer, 1997), (2) college may be the first time these cancer survivors have had
the choice to share or not share their cancer history, (3) disclosure has been shown to impact mental and physical health (Smyth et al., 2012), and (4) limited research has examined the disclosure experiences of pediatric cancer survivors who are now young adults.
CHAPTER 2

METHOD

PARTICIPANTS

Participants for this study were recruited through the American Cancer Society (ACS, 2012a), California Division, Young Cancer Survivor Scholarship Program (YCSSP), and by a nationwide distribution of a study flyer (see Appendix A) to cancer- and college-related venues, list-serves, websites, and social media. Twelve undergraduate college students with a personal history of cancer participated in this study. Participants ranged in age from 18 to 30 years old. Seven of the participants were women and five were men. Seven participants identified as Caucasian, five participants identified as Latino/a or Hispanic, and one participant identified as Asian, specifically Chinese. Participants’ ages at diagnosis ranged from 18 months to 22 years old, and the amount of time elapsed between cancer diagnosis and study interview ranged from 6 months to 20 years at the time of the interview. Most of the participants had a type of leukemia or lymphoma; other cancers were brain cancer, carcinoma of the tongue, dysgerminoma, and endodermal sinus tumor. Of the 12 participants, 10 resided in California. See Table 1 for a description of participant characteristics.

PROCEDURE

Approval for this study was obtained from the Institutional Review Board (IRB) of San Diego State University (SDSU). Participants were recruited via two methods: (1) personal invitations distributed by the ACE YCSSP (see Appendix B) and (2) mass distribution of a study flyer. The personal invitation instructed potential participants to call or e-mail the PI to schedule an interview. The study flyer instructed potential participants to contact the PI via e-mail. Those who contacted the PI were asked to confirm that they met all three eligibility criteria: (1) personal history of cancer, (2) 18 years of age or older, and (3) current college undergraduate student. If they were eligible and agreed to participate in the study, then individual video chat sessions were scheduled with the PI and the consent document was e-mailed to participants for review (see Appendix C).
Table 1. Participant Characteristics

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Gender</th>
<th>Race/Ethnicity</th>
<th>Age</th>
<th>Type of cancer</th>
<th>Age at first diagnosis</th>
<th>Length of treatment</th>
<th>Current year in school</th>
<th>Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>F</td>
<td>W</td>
<td>19</td>
<td>Dysgerminoma</td>
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<td>4</td>
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<tr>
<td>P2*</td>
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<td>8</td>
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</tr>
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<td>22</td>
<td>Leukemia</td>
<td>4</td>
<td>48</td>
<td>3</td>
<td>CA</td>
</tr>
<tr>
<td>P6</td>
<td>M</td>
<td>A</td>
<td>22</td>
<td>Lymphoma</td>
<td>7</td>
<td>5</td>
<td>4</td>
<td>CA</td>
</tr>
<tr>
<td>P7</td>
<td>F</td>
<td>L/H</td>
<td>18</td>
<td>Leukemia</td>
<td>14</td>
<td>28</td>
<td>1</td>
<td>CA</td>
</tr>
<tr>
<td>P8*</td>
<td>F</td>
<td>W</td>
<td>22</td>
<td>Brain</td>
<td>7</td>
<td>1.5</td>
<td>4</td>
<td>CA</td>
</tr>
<tr>
<td>P9</td>
<td>F</td>
<td>W</td>
<td>20</td>
<td>Endodermal sinus tumor</td>
<td>1.5</td>
<td>5</td>
<td>3</td>
<td>CA</td>
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<tr>
<td>P10</td>
<td>F</td>
<td>L/H</td>
<td>22</td>
<td>Carcinoma of the tongue</td>
<td>22</td>
<td>3</td>
<td>4</td>
<td>AK</td>
</tr>
<tr>
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<td>F</td>
<td>W</td>
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<td>Leukemia</td>
<td>10</td>
<td>28</td>
<td>5+</td>
<td>CA</td>
</tr>
<tr>
<td>P12</td>
<td>M</td>
<td>W</td>
<td>20</td>
<td>Leukemia</td>
<td>4</td>
<td>12</td>
<td>3</td>
<td>CA</td>
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Note. W = White, L/H = Latino/a/Hispanic, A = Asian; *Indicates one or more recurrence(s); Length of treatment is in months.

The only record linking participants to this research study would have been the signed consent document, and the principal risk of the study was the potential harm resulting from a breach of confidentiality. Therefore, the SDSU IRB waived the requirement to obtain a signed consent form. Potential participants were instructed to reserve a quiet, private space where they could remain for the duration of the interview. The PI conducted all of the interviews from a locked, private office. At the beginning of the video chat sessions, the PI reviewed the consent document with the potential participant and asked whether they had any questions. The potential participants were then asked to verify consent verbally. None of the consented participants requested a signed consent form for their records. As part of the consent process, participants agreed to being audio recorded. After providing verbal consent, participants completed an interview via Google Video Chat, utilizing a semi-structured interview guide (see Appendix D). The average duration of the interviews was 77 minutes.

During the interviews, the same topics were covered with each participant. The interview began with demographic and cancer-related questions. Next, open-ended questions were asked for the purpose of facilitating dialogue on each topic, and prompts were used to encourage participants to elaborate on their answers. Open-ended questions allowed the participants, instead of the interviewer, to decide which dimensions to use to describe their experiences, thoughts, and feelings (Patton, 1990). Participants were asked questions
concerning their decision to disclose and their perceptions of others’ reactions to their disclosure around the time of their diagnosis, during treatment, post-treatment survivorship, when they returned to K through 12 schooling, and during college. Participants were also asked questions about other related constructs, such as changes to physical appearance, late effects from their cancer treatment, adjustment to college, cancer-survivor identity, and relationships with peers. Lastly, participants were asked for advice they would give other young cancer survivors regarding disclosure. The interview concluded with the opportunity for participants to provide additional comments that they believed to be relevant to the study.

The PI conducted all of the interviews in English. The interviews were audio recorded and transcribed verbatim. Participants were not compensated for their participation. Participants were thanked for their time and asked if they wished to be informed of the results of the study and/or contacted regarding future research opportunities. Participants were provided with a resource sheet that was created by the PI (see Appendix E).

**MEASURES**

*Demographic and Cancer-related Information.* Basic demographic and cancer-related information included current age, race/ethnicity, preferred language, type of cancer, stage of cancer, type of treatment, length of treatment, the amount of time elapsed since cancer diagnosis and study interview, late effects, and subjective mental and physical health status.

*Qualitative Questions.* A series of open-ended questions were developed, which that covered a range of issues related to cancer survivors currently in college and their disclosure of their cancer history. Question development was guided by the cancer-disclosure literature, specifically, Figueiredo et al. (2004), Gray et al. (2000), Jackson et al. (2010), Park et al. (2011), and Pistrang and Barker (1992; 1995). See Appendix D for Interview Protocol.

*Qualitative Questions Adapted from Validated Measures.* Relevant questions from the following measures were reworded to be open-ended questions: Shame and Stigma Scale (SSS) in Head and Neck Cancer, Sense of Stigma subscale (Kissane et al., 2012), Body Image Scale (BIS; Hopwood, Fletcher, Lee, & Al Ghazal, 2001), Student Adaptation to College Questionnaire (SACQ), Social Adjustment and Personal-Emotional Adjustment subscales (Baker & Siryk, 1984), Impact of Events Scale (IES; Horowitz, Wilner, & Alvarez,
1979), and the Fear of Disclosure (FOD) subscale from the Interpersonal Trust Questionnaire (ITQ; Forbes & Roger, 1999). See Appendix D for Interview Protocol.

**DATA ANALYSIS**

Trained undergraduate student research assistants (RAs) transcribed the audio recorded interviews. The data were organized and analyzed using Dedoose, Version 4.5 Web Application for Managing, Analyzing, and Presenting Qualitative and Mixed Method Data. Guided by Consensual Qualitative Research recommendations (Hill, 2012), the PI and a graduate student research assistant (GRA) identified domains and categories using inductive, data-driven analysis. From this initial analysis, the PI and GRA created a coding rubric. Next, the PI and GRA coded each of the interviews using the coding rubric. After coding was completed, an RA completed an inter-rater reliability test on a subsection of excerpts from the transcripts, a function provided by Dedoose, to further ensure that the domains and categories were not idiosyncratic to the PI’s and GRA’s view of the data. Next, cross-analysis was used to identify patterns and themes across cases and to enhance the preliminary findings. After the cross-analysis, the PI reduced the data to essential points, identified final themes, and developed an overall interpretation of the results. Similar methodology (i.e., qualitative interviews and thematic analysis) has been employed by past studies on disclosure (Jackson et al. 2010; Rodkjaer et al., 2011).
CHAPTER 3

RESULTS

The Dedoose test of inter-rater reliability provides a pooled kappa value to summarize inter-rater agreement across many items. Based on a review of the literature (i.e., Cicchetti, 1994; Fleiss, 1971; Landis & Koch, 1997), Dedoose suggests the following interpretation of kappa values: < .50 = poor agreement, .51 - .64 = fair agreement, .65 - .80 = good agreement, and > .80 = excellent agreement (Dedoose, 2013). We achieved a pooled kappa value of .82 based on the coding of excerpts on all domains and key categories, suggesting excellent agreement.

Because of the great diversity within this sample, information saturation has yet to be reached for all topics. Four primary domains were identified: voluntary disclosure during various periods (i.e., diagnosis, treatment, post-treatment survivorship, return to K-12 grade schooling, and college), cancer-survivor-related identity development, belongingness/connecting to peers, and advice to other young cancer survivors about disclosure. Results begin with a description of participants’ experiences of disclosure during college, including level of openness and comfort with disclosure, to whom participants chose to disclose, reasons for disclosure, other people’s reactions to participants’ disclosure, and participants’ feelings about other people’s reactions. Next, possible contributing factors to participants’ college-disclosure decisions are described. Identified contributing factors included pre-college (involuntary and voluntary) disclosure experiences, support during diagnosis and treatment, experiences with other pediatric cancer survivors or children with other chronic health conditions, and physical changes and long-term effects. Finally, cancer-survivor-related identity and belongingness/connections to college peers are described in relation to college disclosure experiences.

DISCLOSURE IN COLLEGE: COMFORT AND OPENNESS

Participants in this study ranged greatly in age at the time of the interview (18 to 30 years old), age at diagnosis (18 months to 22 years old), length of treatment (six weeks to
four years), and time since completing treatment (6 months to 20 years). Participants’ ranged in their level of openness and comfort with disclosure (see Figure 1). Many participants were very open about their cancer experience and were comfortable disclosing their experience with their college peers. For example, when asked to describe examples of sharing his cancer history in college, one of the participants who expressed being very open and comfortable with disclosure stated:

When I was pledging for my fraternity, my main, um, task I had to do was I had to interview in this little book. I had to write down the interviews, like all the answers to the questions. I had to interview every single member of the fraternity. Um, they would all ask me like, “Oh, tell me something about yourself, George.” And, I would tell them. And then I would say, you know, “I had cancer when I was little.” And, so I told maybe about 60 to 70 people, all within 7 weeks, uh, 7 or 8 weeks of pledging. Um, which wasn’t a big deal because I was used to telling people one-on-one that I had, I had, er, I once had cancer. So, that wasn’t a big deal. (P5, 18-year leukemia survivor, personal communication, April 24, 2013)\(^2\)

Other participants were less open about and comfortable with sharing their cancer history. The participant who expressed the least amount of comfort with disclosure took active measures to conceal physical changes that could possibly lead to disclosure:

Uh, um, well, I usually wear long sleeves that cover the scars from the cancer. So, um, like I usually make sure I cover them because they don’t look like normal scars and sometimes I don’t feel like answering their [other people’s] questions, or I don’t want them [other people] to start judging me before they even know what it means. (P7, four-year leukemia survivor, personal communication, May 3, 2013)

**DISCLOSURE IN COLLEGE: TO WHOM**

With whom participants were willing to share their cancer history varied. None of the participants kept their cancer-survivor status a complete secret. Some participants, however, were only willing to tell their closest friends, and others only disclosed on a “need-to-know” basis. Other participants would share their story whenever it was “relevant to the conversation.” When asked about the people with whom he would disclose, one participant responded: “So I just, I mean now I can tell anybody. Um, now it’s not so much about who I

\(^1\) Names have been changed to protect the identity of the participants.
\(^2\) Quotes have been abridged.
disclose it to, it’s, it’s a lot more about when, it’s the appropriate time to disclose it” (P2, seven-year lymphoma survivor, personal communication, March 17, 2013).

Most of the participants expressed an explicit lack of interest in sharing their cancer history with acquaintances or with people they anticipated never seeing again. A few participants described the importance of building a relationship with someone before
revealing their cancer-survivor identity. When asked about people treating her differently, either good or bad, after finding out that she is a cancer survivor, one participant stated:

   Um, people who didn’t, didn’t know me as well before I told them would definitely, you know, talk louder and be a little bit, act as if I was delicate, which is why I don’t like telling people early. Um, but, nothing really, huge. Nothing awful. (P9, 18-year endodermal sinus tumor survivor, personal communication, May 16, 2013)

   Few participants shared their cancer history with their professors; most chose not to disclose or opted to contact their school’s student disability service center, instead of speaking with their professors directly, for an accommodation. When asked whether she had told professors about her cancer history, one participant stated:

   Um, no I have not. Um, I, like, I’m a client with the student disability resources, um, so I get extra time on tests and things like that. So they [professors] know that I have, um, access to that ‘cause I have to have them, like, sign a form at the beginning of the semester so they can make accommodations for me. Um. But I never actually told any of them, like, what, it is that I have. Um, just because I don’t feel like they need to know, you know. Like, as long as I, you know, get to have my accommodations, like, I don’t think they need to know why it is that I have them. (P8, 15-year brain cancer survivor, personal communication, May 1, 2013)

   One participant described faculty members as the most challenging people to whom she had disclosed in college. Reasons for an unwillingness or hesitation to disclose to faculty members included perceptions of professors’ lack of interest in “personal stories” and fears of being “treated differently than other students.” Participants who had opted to tell their professors received mixed responses. For example, one participant described how, despite the positive responses she had received, negative responses discouraged her from reaching out for assistance in the future:

   Uh, but, at one point, I was having trouble finishing tests on time, which I’ve never, ever had trouble with before. So, I talked with one of my professors, and I told him what had happened to me. And, you know, he, he said, “I had no idea.” And he was really helpful throughout, um, the rest of the semester. Um, but, I had another professor, who, who I told, and I said, “Can I make up this test?” Um, ’cause I ended up getting shingles during spring break. So I, I, I got shingles, and I, my doctor put me on really heavy painkillers since it was so painful. And then, since I was on painkillers, that helped me even more to not be able to focus right. So, um, I had a, I told one of my professors, who said, “Yes, I’ll do everything possible to help you.” And I told another one. He said, “Sorry. Too bad. You’re just gon na have to take, take the test like everyone else.” So,
they were polar opposites. I felt like after, after I talked to that one professor who said, “Too bad,” I felt, like, he just didn’t believe me. And, um, I had asked for, one of the, like, administrators, I had asked him for help with something, and I had told him, “This is what I’ve been through. Um, is it possible for you to help me?” And he, he, he was kind of, made me feel like he didn’t believe me either. So, they, there’s a, unfortunately, there’s a lot of, assumptions that go, that go on, and the, he didn’t ask for proof or anything, which I could have easily given him proof of when I had been in treatment. But he just kind of said, “Nope. Can’t help you.” So, it, I was just kind of, not really wanting to approach anyone else after that. (P10, six-month carcinoma of the tongue survivor, personal communication, May 21, 2013)

**DISCLOSURE IN COLLEGE: WHY AND WHY NOT**

Some of the most common reasons for disclosure included helping others through their story, spreading awareness of pediatric cancers and related issues, and participating in community service. When asked about current reasons for sharing his cancer history, one participant stated: “Um, either to enlighten people or get people to be more active and help cancer research or, um, participate in community services that are related to cancer, um, for people to stay healthier” (P6, 15-year lymphoma survivor, personal communication, April 24, 2013).

Another reason survivors disclosed was the need to obtain different types of accommodations, such as making roommates aware of possible health complications and emergency information or asking for help with coursework. Responding to inquiries about visible cancer-related physical manifestations and explaining something related to one’s cancer experience were often given as reasons for disclosure. When asked about current reasons for disclosure, one participant said:

Um, currently just because of my hair. ‘Cause I don’t like it, so when people complement on it I’m, like, “Oh, well, I hate it.” “Well why’d you cut it?” “Oh it fell out; it wasn’t my fault.” Um, that’s basically the main reason, which is super frustrating ‘cause I don’t want to give in to the peer pressure of “oh you look the part so you must be it.” But at the same time it’s kind of the easiest way and makes the most sense to me. (P4, six-month lymphoma survivor, personal communication, April 23, 2013)

Survivors often reported disclosing because of the nature of the relationship with their friends and the expectations of the relationship:

They’re also people that are very, very important to me, and very dear to me. And, I, it’s something like, if this happened to them, I would expect them to tell
Participants also disclosed because of personal characteristics, such as generally being an open person. Lastly, correcting possible misconceptions was another reason participants decided to disclose. When asked about the experience of telling his current girlfriend about his cancer history, one participant responded:

So it was, I just talk to her, you know, find the right way to tell her and everything. And, um, just kind of inform, yeah. She kind of knew already, I believe so, by one of my friends, yeah. Uh, she kind of knew already, um, so I guess that I had to tell her, uh, more in depth, in details, because you want, you want to inform people because, if not then, they feel like, “I don’t want to get to know you,” you know, “I don’t want to talk to you.” But to get rid of that misconception, you gotta be straight and be honest, and tell them what it is, and how it got cured and, where are you right now, and what are your plans and everything. And just, basically proving you’re, that you’re a normal person again, right? (P3, six-year leukemia survivor, personal communication, March 15, 2013)

The main reason participants chose not to disclose in college was to avoid possible unwanted reactions, such as judgment, pity, being associated with negative assumptions about cancer survivors, or being perceived as different. This is how one participant described her reasons for not telling people about her cancer history:

Um, I think the main reason is that I think that it’s like a really private thing. Um, to talk about and I, I don’t want anyone to feel uncomfortable or awkward. Um, I don’t want people to think differently about me or my abilities. Um, I don’t want them to make, put me, like, in a certain group of people just because I had cancer. (P8, 15-year brain cancer survivor, personal communication, May 1, 2013)

When asked about making friends in college, one participant responded:

I don’t want people to feel sorry for me, that’s one of my biggest things. I don’t want people to say, “oh my god, you’ve had cancer? I have to be your friend.” That would just drive me insane. I don’t like people to feel sorry for me at all, and that was another reason why I didn’t tell people at first, was I didn’t want people to say, “Oh, you poor thing! That’s the worst thing that could ever happen!” Which, yeah, it is, but don’t tell me that, I already know. So, I, don’t like people to act like I’m a victim ‘cause I’m not a victim. I’m a survivor. There’s a big difference. (P10, six-month carcinoma of the tongue survivor, personal communication, May 21, 2013)

When asked about his reasons for not disclosing his cancer experience, another participant said:

No, I have no reasons. Uh, if there were any reason, it would be because it, uh, probably, like, I don’t want them to think that I’m abnormal. But I know I can
prove myself normal, in anyway they want. Yeah. (P3, six-year leukemia survivor, personal communication, March 15, 2013)

When asked to clarify what the participant meant by “abnormal,” he said:

Yeah. People, people sometimes can think that cancer is, like, contagious, probably, or something like that. They want to stay away from me. But, they, it’s ‘cause they don’t know. And usually I found out that people want to know, they want to know more about cancer. Every person that I talked to, they started, as soon as they, they, um, noticed that I’m a cancer survivor, they start asking me questions. (P3, six-year leukemia survivor, personal communication, March 15, 2013)

An additional reason why participants chose not to disclose was that they felt like they didn’t know how to tell people:

Um, so I wanted to tell people, but, I didn’t. As I’ve been saying, I didn’t wanna, like, sit them down, and then, like, this is the story of my life. Um, I think I would just wait for opportunities for it to come up naturally. (P9, 18-year endodermal sinus tumor survivor, personal communication, May 16, 2013)

Lastly, survivors avoided telling people who gave them the sense that they wouldn’t be receptive to, wouldn’t care about, or wouldn’t understand the survivor’s story. When asked about reasons why she wouldn’t tell people about her cancer history, one participant said:

Um, if I don’t have enough of a connection with them, I don’t want them to view me as the cancer girl, and so I don’t, I don’t share it. Um, and if I don’t think they’ll be interested in it, then I don’t share it. Um, like, you know, if I told somebody, and they’re, like, “Oh, okay. Oh, cool.” And then would just not ask me follow-ups. ‘Cause, like, I want someone to ask me questions about it. Not because I want them to, you know, know more about me, but I want them to understand more about what it is to be a cancer survivor and go through treatment and go through follow-ups. (P9, 18-year endodermal sinus tumor survivor, personal communication, May 16, 2013)

**DISCLOSURE IN COLLEGE: OTHERS’ RESPONSES TO DISCLOSURE AND PARTICIPANTS’ FEELINGS ABOUT OTHERS’ RESPONSES**

The most common reaction by others to participants’ disclosure was shock, ranging from surprise and awe to skepticism and disbelief. Disbelief wasn’t always explicitly stated by the other person, but interpreted by the survivor. Some participants were amused by people’s disbelief; others were frustrated and hurt that people thought that they were lying.
When asked to describe experiences of telling people about her cancer history, one participant responded:

Um, even now when I tell people in college, they, like, don’t believe me. Like, they think I never had cancer. They say, “You look perfectly normal, like all of us.” And it’s kind of a shock. The common reaction is like, “No. You don’t, you never had cancer. You look perfectly normal.” (P7, four-year leukemia survivor, personal communication, May 3, 2013)

When asked about other people’s reactions, one participant stated:

Um, at first they thought I was joking, and then I usually have to, like, if people think I’m joking then, I usually have to show ‘em my scars so they see proof. Um, I guess it’s kind of entertaining [soft laugh], yeah. When people don’t believe you. (P6, 15-year lymphoma survivor, personal communication, April 24, 2013)

When asked if he had any bad experiences of his cancer history, another participant said:

I had bad experiences, where the most frustrating times I would tell people, um, would be the times that I feel like they think I’m lying. You know, there were some times, like, where, yes, yes, um, that I felt like people thought I was lying to them about having cancer. And that was so frustrating. I’m, like, I’m not. They never said I was lying. It was just me being presumptuous on them. Thinking, on, on their reaction led me to think like they thought I was lying. They didn’t say “Are you serious?” or “re you really, are you, is that real?” Um, but, um, I got a very, very strong feeling that they thought I was lying. And so that was, like, the worst reaction ever. You know, I felt very, like, um, hurt, you know, like, um, devalue-ized, devalidized [sic], like my story is not real or they don't think it’s real. So, yeah, that was definitely the most frustrating time that I ever tell people. (P2, seven-year lymphoma survivor, personal communication, March 17, 2013)

Several participants described how others were impressed by their cancer story. When asked about recent disclosure experiences, one participant said:

Um, I recently told a couple people in my English class, and, they were like, “Really? You, you had cancer? That’s awesome! And you, how old were you?” I was like, “Fourteen.” They’re like, “Wow. You went through it, and you made it through.” And I was like, “Yeah.” And they’re like, “That’s awesome. I’m proud of you.” (P7, four-year leukemia survivor, personal communication, May 3, 2013)

Further, some participants expressed difficulty accepting people’s positive judgments. When one participant was asked how he feels around the people who know he is a cancer survivor, he said:

I feel like, they sometimes see me as a very strong person. Just ‘cause, um, I survived cancer. Um, I guess, a pretty courageous thing to do. But it’s, sometimes, it’s hard for me to, I guess, accept that. Um, just because, sometimes,
like, I feel I was so little that it wasn’t so much a choice to go through the
treatment. Like I, I didn’t know what was going on. So, I, it’s sometimes hard for
me to accept that I was being so strong or courageous, but really, I didn’t really
know what was going on. So, I don’t know. It’s kinda hard for me to accept.
Yeah. (P12, 16-year leukemia survivor, personal communication, June 16, 2013)

Similarly, when asked to describe her first disclosure experience in college, one participant
said:

I’m not sure, but I have this vague idea it was in my art class. And, I don’t know
if the subject was brought up, or what it was. But, I think it was a guy in my art
class, and he had a really positive reaction too: “Oh that’s so amazing! That’s so
cool. You’re a cancer survivor.” Um, I just can’t really remember the
conversation, or why it was brought up, or who brought it up. Uh, it seemed to me
like it was, it was a positive interaction. I think I was a little bit surprised that it
was so positive. You know, when I get the reactions like, “Wow! That’s
amazing! Congratulations!” it, it’s almost like you don’t know what to say
sometimes. Like, I didn’t win a marathon. I just did what I had to do. (P11, 20-
year leukemia survivor, personal communication, June 11, 2013)

Other reactions included pitying the survivor, asking questions, expressing
acceptance and understanding, and “freaking out.” When asked about the reactions she has
received, one participant said:

I’ve gotten mixed reactions from the, people that I’ve dated. Um, some of them
have been like really good about it and just been like, “Oh ok,” you know, like,
“Thanks for telling me,” like, “Do you want to talk about it?” And usually I’ll say,
“no, unless you have something to ask me about it.” Um, but there’ve been a
couple that have, like, really freaked out about it, like “Oh my god,” like, “Are
you dying? Are you okay?” like, “Do you still have it? Can I do anything to
help?” And that, like, really bothers me because it feels like patronizing. I mean,
like, I know that they’re doing it out of, like, a good place and everything. I just
don’t like it. (P8, 15-year brain cancer survivor, personal communication, May 1,
2013)

**Pre-college Disclosure Experiences**

From the time of diagnosis through treatment and into college, some participants
became more open about sharing their story, while others became more private. A few of the
participants described an evolution of their feelings about disclosure, from being secretive
and embarrassed to being open about their cancer experience in college. A few participants
who were already comfortable sharing their stories before college remained so in college.

When asked about pre-college disclosure, one participant said:
In junior high through high school, it was only the people I was closest to. I felt that people I didn’t know very well needed to know, because a lot of people who don’t understand what cancer is make a lot of judgments about what a cancer survivor can and cannot do. And I really didn’t want to have it as something negative against me. I also didn’t really understand what is it to be a cancer survivor, you know? I used to feel embarrassed about, about it if people found out, because I don’t, I, I don’t know why. I used to feel almost ashamed about it, even though obviously it was not my fault. But then, uh, going into junior college and other college beyond that, when people were more mature, I had a much easier time talking about it. And I, the, the main difference was when I told the first person I told in college, said something like, “Oh, wow! My aunt had breast cancer, and that’s so amazing you’re a survivor,” and “Good for you.” I got all this positive feedback. Whereas, if I told somebody in high school, they kind of wouldn’t get it. So, there’s a vast difference with maturity level. (P11, 20-year leukemia survivor, personal communication, June 11, 2013)

When asked about disclosing before starting college, one survivor described how other children had no experience with young cancer survivors, only with older cancer survivors, such as, their grandparents, and how their reactions led her to believe cancer was a bad thing:

   Um, I think people, people ask if it’s, like, contagious. Um, uh, um, you know, like, what else there’s. You know, like, if I can get it again, if, even if I’m better, can they still get it. Um. I don’t know. Just, the idea that they could get sick from me, like, I was a germ or something. (P9, 18-year endodermal sinus tumor survivor, personal communication, May 16, 2013)

When asked about whether she thought about sharing her cancer history with others in college, one participant described an earlier experience with disclosing that made her not want to disclose in the future:

   Yeah, in, in high school, um, there was this, time where, um, a teacher I had in 10th grade, I had in 11th grade, and she said, “Tell me, talk about yourself.” And one time, I said, “I’m fighting cancer at the moment.” And this one girl started talking about me behind my back, saying, “She’s only saying it because she wants attention.” And that’s when, that’s why I, like, kept it from anyone unless they, like, asked about it, or they saw something and asked about it. (P7, four-year leukemia survivor, personal communication, May 3, 2013)

**EXCEPTIONAL SUPPORT DURING DIAGNOSIS AND TREATMENT**

A few participants described receiving exceptional support during their diagnosis and treatment from hospital staff, their family members, or friends. These early experiences seemed to be related to participants’ comfort with disclosure and openness about their cancer history. Each of the participants who described receiving exceptional support early in their
cancer experience, later in the interview described being open about their cancer experience in college. When asked how much his cancer experience disrupted his life, one participant said:

Besides having to redo kindergarten, um, I would honestly say City of Hope did an amazing job at making sure that my life, I had a good childhood still, regardless of living in a hospital basically for, you know. I lived there for almost a whole year, and then after that, it was 3 weeks off, 3 weeks in, you know? And uh, I, they honestly did an amazing job, you know, entertaining me and making me feel like I was just at a second house. So, I would say that it didn’t impede it at all. (P5, 18-year leukemia survivor, personal communication, April 24, 2013)

When asked about whether his parents talked with him about his treatment, one participant stated:

Yeah, so they, they would definitely keep me in the loop of what’s, what’s going on. Um, they didn’t, they didn't ever at all say, “Go do this.” And not explain why. Um, and they were very supportive. Like every single night, either my mom or dad, or most times both, would pray with me every night. And, um, like I said before, my mom would always, if I had a need or a want that needed to be fulfilled because of the chemo, um, she would never once, um, show any sign of, um, disliking, at all, or she didn’t want to. She always was there for me. (P12, 16-year leukemia survivor, personal communication, June 16, 2013)

When asked about coming back to school after completing treatment, one participant emphasized the support she received from her close friends:

Um, different? You know, I was. When I came back, my hair was growing back, so I was still bald when I first came back, and, you know, still got a lot of stares, but from strangers. But I still had a lot of support from my friends, and I think that's all that really matters, that my friends were there. You know? The true friends, the ones that stuck around. Um, and I felt, like, welcomed by them and, yeah, like it wasn't easy because everyone in high school is so judgmental. I mean, not that it goes away when you’re in college, or when you’re adult, you know. Like, people are judgmental everywhere you go, no matter what age, but, um, it was just my close friends helped me get through it, you know? (P1, three-year dysgerminoma survivor, personal communication, March 16, 2013)

The relationship between early support and disclosure in college is only speculative and not well established. However, interestingly, these survivors did express more openness than other survivors in the sample. It may be the case that these early supportive experiences allowed the survivors to perceive their cancers in a more positive way, which contributed to more openness about their cancer experiences.
RELATIONSHIPS WITH OR AWARENESS OF OTHER PEDIATRIC CANCER SURVIVORS OR CHILDREN WITH OTHER CHRONIC HEALTH CONDITIONS

Other survivors emphasized the importance of a relationship with another young cancer survivor or with a young person with another chronic health condition or simply of the awareness of other young cancer survivors. Participants described that it was easier to discuss their cancer with someone who could directly relate to their experience. When asked about her best experience sharing her cancer history, one participant said:

Um, I think my best experience, um, was probably sharing it with my, like, my best friend now who had the heart problem, just because it was easy to talk about, because she had so much of, like, a similar story. And, she was very much of the same, like, you know, I’ve had this since I was a kid. Like, this is just part of me, it’s not something that’s bad or good. It’s just something that is part of my life, like, it’s who I am, that kind of thing. So, um, that was like the easiest person that I told it to, just ‘cause she was very good about, like, feedback, and, like, we had a really good rapport. (P8, 15-year brain cancer survivor, personal communication, May 1, 2013)

When asked about disclosing her cancer history before college, one participant described how attending camp changed her perspective:

Um, I think I became a little more comfortable with it. I started going to a camp for cancer, for people who have or had cancer, when I was in fourth grade. And I think that made me a lot more comfortable with it. And, so it taught me a way to embrace it, rather than think of it as a bad thing. And, anyone who thinks it’s a bad thing, that’s their problem, and not mine. Uh, I think the thing about camp was that you don’t have to, that big secret that I felt uncomfortable sharing in elementary school, it didn’t even need to be brought up. And it, I didn’t need to find a way to, like, sit down with my best friend and be, like, “Hey, I went through this, just to let you know.” Um, it’s sort of, all these people have cancer, and we don’t, you know, that whole weight is lifted off of our shoulders because we all know that, in order to be at camp, we had to go through that. And then I was also able to see people going through treatment during camp. And so I could understand more of what I went through and what my parents went through, because I got to see what they were going through. I had a new perspective, because, if someone was going to judge me for what I went through, then I always had that camp to go back to, and my friends that understood what I went through, and my family. And those people need to figure out cancer for themselves. And I am not gonna, you know, give in to, you know, believing that I’m gonna give them cancer or, you know, damage their life because of what I went through. (P9, 18-year endodermal sinus tumor survivor, personal communication, May 16, 2013)
Participants also expressed that seeing other cancer survivors thrive altered their perspective of cancer survivors, giving them the confidence to openly identify as cancer survivors. When asked about when she started to feel like a cancer survivor, one participant said:

I won the American Cancer Society’s Young Cancer Survivor Scholarship, and that was the first time I had really been connected to American Cancer Society or several other cancer survivors. And I remember the award luncheon was somewhere in L.A. in a nice hotel. And so, there was this room full of college kids, my age, who were cancer survivors, and they were, um, doing all these great things in college. And that’s when it started to dawn on me that being a cancer survivor didn’t necessarily have to limit what I could do, or, you know, seeing that all these other people were doing great things and had high grades, as I had always had high grades, it made me feel that, it was okay to tell people that I’m a cancer survivor. You know, to see all these positive examples of others. Uh … so yeah, probably 2001, 2002, when I got that scholarship. (P11, 20-year leukemia survivor, personal communication, June 11, 2013)

When asked about who she would consider to be her main social support person, one participant stated:

Um, um I would call Amy. I met her through treatment. She was diagnosed the same week with me with Hodgkin’s, and we kind of just became best friends. I would say she was, she’s now like my best friend; I would, yeah, most definitely. And I can’t really talk about cancer things with my friends here, just because they just don’t know. It’s way easier and way more comfortable to talk to someone who knows exactly what I’m going through. So that’s who I’d call. (P4, six-month lymphoma survivor, personal communication, April 23, 2013)

**Physical Changes and Long-Term Effects**

Participants’ physical changes often led to questions from other people. When asked about her physical changes, one participant said:

Um, if I think whenever [I] have someone stare at my discoloration for too long, I’m just kind of like, “I had radiation.” They’re like, “Oh my god! But you’re so young!” Every time! And, like, I just have to explain to them, like, everything that happened and I’m, I’m okay with it now. But, um, I kinda do want, ’cause right after I had surgery, um, I hadn’t had radiation yet, so I still had long hair that I had to put up. And one of my old managers from Game Place came up to me and was like, “What happened to your neck??” And I said, “Oh I had surgery, because I have cancer.” And I explained the backstory, and he’s like, “Girl, I just thought you had a bad boyfriend or something.” And I was like, “Oh my god!” [laugh] You know, but then I would explain, no, I didn't have a bad boyfriend, I had surgery, you know. And he made me laugh with that, and that helped too. But, um if, like, if people ask about, whenever I have long hair and I put my hair up, I’m sure someone’s going to ask what happened. I’ll be able to tell them, and
I’ll be more ok with being able to tell them about it. (P10, six-month carcinoma of the tongue survivor, personal communication, May 21, 2013)

Several participants reported struggling with late effects, such as cognitive and memory problems, and fatigue. Participants described how these late effects hindered their academic progress and ability to relate to their healthy peers. One participant highlighted the multidimensional influence of physical effects. When asked about development and pre-college school progress, one participant stated:

Yeah. Um, I was always self-conscious about my scars, ‘cause I have a really big one across my stomach. Um, and because of my hearing loss, I can’t hear high frequency sounds. So, I can’t hear, like, S’s and Z’s, and the difference between SH and CH and stuff like that. So I had to go to speech therapy during school. Um, and I was supposed to wear hearing aids. I didn’t because people kept asking me about them, and I didn’t want to answer the question. So, I’m sure that altered the, my ability to learn, as well, because I didn’t wear hearing aids elementary through most of high school. Um, and then, also, I remember when I was younger, just being, like, I don’t know what a normal life is like, because I’ve always been in a hospital, and I can’t hear as well as everyone else, and I have these scars, and. It’s interesting because people that go through treatment when they’re older, you know, remembering the before and after. For me, I don’t even, know what the before is like. Yeah. (P9, 18-year endodermal sinus tumor survivor, personal communication, May 16, 2013)

When asked about how she felt about her peers, one participant stated:

Um. Most of them I feel like they don’t quite understand what I’m going through or what I deal with, you know, health-wise. Or, um, they just can’t grasp what it is to be exhausted all the time. Or, you know, if I don’t get a full 8 or 9 hours of sleep, I’m, if I, I, I barely function sometimes. My alertness, is drastically changed if I get, gosh, 5 hours of sleep. And I can’t even tell them about that because they’ll be like, “Oh, well, I only got 4 hours of sleep,” like they’re trying to compare their perfect health with my health after going through chemo and all that. So, sometimes it’s hard to identify with them. I can’t remember the original question. I’m sorry. It’s just, yeah, harder to relate to them. It’s, I feel like that’s the chemo brain, too. I’ll lose track of, what the, what the question was. (P11, 20-year leukemia survivor, personal communication, June 11, 2013)

Other survivors noted how their physical changes or lack of physical changes influenced others’ perceptions of them. When asked about his disclosure experiences in college, one participant reported:

So, actually it was about, I wanna say, a week or two ago. I was walking with my my friend, um, who I met only a few months ago, and, um, I can’t really remember how it came up, but I’m, I said that, um, I had cancer. Um, and he was very shocked and surprised. And, um, so, I guess I just kept explaining, “Yeah, I
had cancer when I was little and, for about four years, and I’m all good!” And he was pretty impressed, I guess? That’s a, a common expression I, I see for people. They’re very, not just surprised that I had it, but impressed that I’m doing so well. And, they can’t even tell. I guess people don’t have cancer kind of expect that they would see the after-effects of somebody who had cancer. Almost like they had a surgery, they would see a physical change. So, um, I think that’s, that’s why people look so surprised when they see me, and I said I had cancer and they’re almost skeptical. Yeah, yeah, they expect me to be, I guess, all weak and stuff. (P12, 16-year leukemia survivor, personal communication, June 16, 2013)

In contrast, when asked about how she felt about her cancer experience in the present day, one participant said:

I think it’s positive. Um, I can’t wait to not look the part, though, because physical appearance is such a huge thing with treatment. And it just changes you a lot, and it’s just, I don’t like it. I think it blows my mind how that just losing your hair makes people so much differently; ‘cause when they didn’t know I still had cancer, I just had long hair. So, I think it’s positive, but I can’t wait for the next year when I don’t look the part, but still have the same like changed personality and views. (P4, six-month lymphoma survivor, personal communication, April 23, 2013)

**CANCER SURVIVOR IDENTITY**

Participants’ definitions of “cancer survivor” varied. Some participants felt strongly that one is a cancer survivor only after one finishes treatment; other participants agreed with the National Cancer Institute’s definition: A person is a cancer survivor from the time of diagnosis until death. Moreover, some participants felt that the distinction between “patient” and “survivor” was very important. When asked whether she felt differently about disclosure during pre-college years and college years, one participant said:

Um, I feel better about interacting with people now than I did before. ‘Cause people are more mature, and, uh, I’m a survivor, not a patient. Um, like, if you say you’re a cancer patient, people think you’re, like, looking for attention. And when you say you’re a cancer survivor, people are like, “[Gasp] You beat cancer! You’re awesome!” That’s my experience. (P7, four-year leukemia survivor, personal communication, May 3, 2013)

Participants also varied in the way they thought young cancer survivors are perceived. When asked about perceptions of young cancer survivors, one participant said:

Um, well, one of the reasons I don’t really like to talk about it is, because I think that they perceive cancer survivors in general, like, as people that have had, like, traumatic things happen to them, and, like, they are really sad people, and they need to be pitied, and things like that. And I just hate that perception. Um, so, I
don’t really like it. Um, it’s, I don’t know, like, I, I don’t know. I just feel like, most of the time people think that it’s like a bigger deal than it is, and to me it’s not a big deal. So, it makes me uncomfortable for people to be like, “Oh, yay for you.” It’s not that big of a deal, like, it just happened. (P8, 15-year brain cancer survivor, personal communication, May 1, 2013)

Conversely, when asked the same question, another participant said: “I feel like other people see cancer survivors as very fortunate people who are very strong” (P12, 16-year leukemia survivor, personal communication, June 16, 2013).

Although every participant identified as a cancer survivor to at least some extent, the degree to which “cancer survivor” was a centralized identity varied. When asked if she identified as a cancer survivor, one participant said: “Yes! Very proudly!” (P1, three-year dysgerminoma survivor, personal communication, March 16, 2013).

When asked the same question, another participant said: “Yeah! Yeah” (P12, 16-year leukemia survivor, personal communication, June 16, 2013).

However, when the same participant was asked when he started to feel like a cancer survivor, he said:

Recently, um, I would, participate in Relay For Life. And I’ve been doing that for many years. And every year or at every Relay For Life, the opening lap starts with the cancer survivors. And it was really tough for me sometimes to do that lap, because I, I think it’s still, I don’t really feel like I’m a cancer survivor, just ‘cause I can’t really remember much of it. Um, it’s almost I wanna say like a dream, like I have very, very faint memories of it. And so, it’s tough, I mean, to accept that, not just because I don't, I, I’m in denial, just ‘cause I don't remember it, too well. So it’s hard to me, it’s hard for me to associate myself with other people who are, are, much older and have really experienced the, the awful effects of cancer. So, yeah. Yeah! I’m still trying to embrace, I guess, or accepting that, um, I am in fact a cancer survivor, no matter the degree, or how much, you remember it. (P12, 16-year leukemia survivor, personal communication, June 16, 2013)

When asked if she identified as a cancer survivor, one participant said:

Yes, I guess yes and no. I, I mean, it makes me uncomfortable when people say that, because they feel like. I don’t know. I feel like when people say that they think it’s like a big, like great accomplishment and. I, I don’t know. I just don’t. I mean, I know that I am one, like, I lived through it or whatever, but I don’t think it’s like a great, I mean, I don’t think it’s a great accomplishment. I mean, like, people live through things every day, and I think that it’s kind of the same thing, you know? (P8, 15-year brain cancer survivor, personal communication, May 1, 2013)
Some participants described attending events, such as cancer survivor camp, community service activities, or American Cancer Society, Relay For Life, that helped them establish their cancer survivor identity. When asked when he decided or started to feel like a cancer survivor, one participant explained:

Uh, probably my senior year in high school was when I really, ‘cause I had always told myself I was a cancer survivor. But, my senior year in high school was when I really started to being extra proud about it. Extra proud, extra outspoken. Um, I started, just, uh, you know, in my senior year of high school; I hosted a blood drive. At that point, I was the only 18 year old in my high school, so I was really the only one legally allowed to do it. And uh, yeah, I hosted the largest blood drive my high school had ever had. And, I think it’s just from there, it picked up, you know. I got, I developed my little philosophy in regards to being a cancer survivor. And I, I, just from there, it’s taken off. (P5, 18-year leukemia survivor, personal communication, April 24, 2013)

**BELONGINGNESS AND CONNECTING TO PEERS**

Participants varied in their perceptions of their college peers and their perceptions of their peers in comparison to themselves. Many participants expressed feeling different from their peers either because of physical changes and limited capabilities or because of their life perspective and, values, health concerns, and lifestyle choices. When asked how she felt about her peers, one participant said:

Um, well, at first it was just like I didn’t like anyone, because they had such strong opinions right away of me. They didn’t even let any. Like, I would, I think I told my floor that I was sick just because, if the, when I was first here, I was really immune-deficient, so any kind of sickness, I would catch in the hall. So, I had to tell everyone that, you know, if you have the flu, you gotta let me know so I don’t go near your room. So, I guess it was hard. And I’m not friends with any of them because they really couldn’t, I mean, college is a big enough adjustment for everyone to deal with. Like, a new friend that also has cancer, that’s going through treatment, is kind of a lot to ask of people, which I understood. So, at first, I guess, I was really focused on school and getting done with treatment and not as much on the friends aspect, ‘cause I knew it was gonna, it wasn’t gonna happen at that time. So, I don’t blame them. Like, I, I would never say it was their fault for not accepting me, but, yeah. (P4, six-month lymphoma survivor, personal communication, April 23, 2013)

When the same participant was asked how she felt about her peers in comparison to herself, she responded:

I think I’m more grown up than them in ways, just because I’ve already had to deal with this. But once again, it’s really not their fault that they haven’t, um, I
mean, I envy them sometimes, just because they get to live the normal college teenager life. But, at the same time, I’d rather take my views and, like, what I’m striving for now, rather than to not know what it was like. I think about that a lot actually, if I was never sick, a lot of things wouldn’t have changed, and I don't know who the person I would be right now and I don't think I would like her. (P4, six-month lymphoma survivor, personal communication, April 23, 2013)

When another participant was asked about her peers, she said:

Um, I kind of see the college life a little differently now, because being a college student, you’re pretty much expected to just go out every weekend and party and go to parties. And I don’t do that at all. And coming back, I see people of course on Facebook; social media is all we communicate with now. Um, so I’ll see them on Facebook posting, um, “Oh, I got so drunk last night.” And, yeah, um, I just, I just wish people would do something better with their time instead of just “I’m gonna go out and get drunk every weekend.” Like, go help someone, go volunteer, which is a little critical of me, because before I had cancer I didn’t go volunteer. But, I also didn’t go out and get drunk, like, I didn’t do that; that just doesn’t interest me. I mean, but it just bothers me that people could have someone in their life that is going through something like cancer, or maybe they have, like, a granddad that has Alzheimer’s, or something. And they’re just kind of like, “Eh, that’s their problem, and I’m going to go out and party, because this is my life.” I just think that people should be a little more aware of what’s going on around them. (P10, six-month carcinoma of the tongue survivor, personal communication, May 21, 2013)

In contrast, some participants felt that it was easier for them to connect to people who were having difficulties than to feel disconnected from their peers and others because of their cancer experience. When one participant was asked about the characteristics of a person to whom he might disclose, he said: “Um, maybe someone who is struggling through something, and then I can help relate to them, or, like, help them realize that I could relate to them by explaining what I struggled through” (P6, 15-year lymphoma survivor, personal communication, April 24, 2013).

Other participants felt the same as their peers. A few participants felt that they were in the “same boat” as their peers or that there was no difference between them and their peers. When asked to compare himself to his peers, one participant said: “I feel pretty equal, I guess, to them. I don’t feel any, um, disadvantages or advantages. I feel, um, I guess, equal” (P12, 16-year leukemia survivor, personal communication, June 16, 2013).

When asked how she felt about her peers, another participant said: “They’re all really nice and really cool and smart. And I’m lucky that I have nice friends who can help me with
chemistry still” (P1, three-year dysgerminoma survivor, personal communication, March 16, 2013).

ADVICE TO OTHER YOUNG CANCER SURVIVORS ABOUT DISCLOSURE

Finally, participants were asked what advice they would give to other young cancer survivors about disclosure. Participants provided a wide-range of advice. The advice that each participant provided suggested which elements of disclosure the participant felt were most important. One participant highlighted the importance of reaction to disclosure as a determinant of who was worthy of friendship: “Uh, if they tell someone and that person has, uh, negative comments or feedback, they’re not worth being friends with. And if they do, like, accept it, they’re, like, friend-worthy” (P7, four-year leukemia survivor, personal communication, May 3, 2013).

Another participant emphasized the importance of personal comfort: “Um, I would tell them to not share with people that they’re not comfortable with. Just don’t let anyone pressure you into doing something that you’re not ready for” (P8, 15-year brain cancer survivor, personal communication, May 1, 2013).

Another participant emphasized the importance of sharing one’s story to raise awareness and to build connections and relationships:

I’d say, get connected. Don’t hide this part of your life because it’s such a big part of it. And we’re the age of people who need to bring awareness and who need to step up and really talk about it and share stories. Like, the connections that I’ve made through Facebook and Twitter are lifelong connections. And people who really know what you’re going through can help you through it a lot more than you’ll ever know. When I was told there was another, um, cancer patient on my floor that was the same age, I was, like, I don’t care. I don’t want to meet her just ‘cause I was sick. But now, after meeting her, like I’ve, I don’t know what I would have done if I wouldn’t have met her. So, definitely get involved, because it’s a good thing to be involved in. (P4, six-month lymphoma survivor, personal communication, April 23, 2013)

Lastly, one participant encouraged other survivors to be proud of their experience and stressed how sharing one’s story can be a positive experience.

Um, don’t be afraid because everyone, everyone knows someone that’s going through it. Um, I would never; I would encourage people to be extremely proud of it, because you’ve achieved something so miraculous, so difficult. And, uh, I honestly feel like, from, from, uh, surviving cancer that you will find there is
really no other obstacle in life anymore. So, don’t be afraid to do it. Um, you’ll be surprised how many doors it opens up, how many people you’ll meet, how many lives you’ll change. And, it has a very, very strong impact on you, emotionally, uh, mentally. I would say, um, telling people about your cancer history would probably be the best thing I’d do on a regular basis. (P5, 18-year leukemia survivor, personal communication, April 24, 2013)
CHAPTER 4

DISCUSSION

GENERAL DISCUSSION

Pediatric cancer survivors will most likely live through their adulthood while facing the effects of their treatment. Survivors will not only have to deal with physical effects, but also psychosocial challenges. The aim of this study was to provide insights into the previously unexplored topic of disclosure among cancer survivors who are in college. The study was designed to obtain descriptive information about survivors’ disclosure experiences, cancer-survivor identity development, and survivors’ feelings about and relationships to their peers.

Disclosure is a complex topic. Survivors in this study varied greatly on each identified theme. Although no participant was completely private about his or her cancer history, the degree to which each participant was comfortable with and desired to disclose was markedly different. Survivors also provided many different reasons for disclosing their cancer history and to whom they chose to disclose. People’s reactions were a key component in survivors’ decisions to share or not share their cancer histories. The most common reason for not disclosing one’s cancer history was to avoid unwanted reactions. The type of reactions considered unwanted varied by participant. Different forms of shock were the most common reactions survivors received. Participants’ stories suggest that cancer doesn’t align with people’s schema of a young person. Some participants even experienced skepticism from their peers and adults. Of the participants who described experiences when people didn’t believe they had cancer, some were amused by such reactions, while others were frustrated and hurt. Since shock was the most commonly reported reaction from others to survivors’ disclosure, more public awareness of young cancer survivors may be necessary.

Possible contributing factors to participants’ college disclosure decisions were also identified. First, as Chaudoir and Quinn (2010) have noted, early or first disclosure experiences often set the course for subsequent disclosure experiences. Participants who received negative responses early in their cancer journey adversely affected future decisions...
about disclosure. Additionally, when discussing disclosure experiences before college versus during college, participants acknowledged the role of maturity. For instance, participants noted that college students were often more mature and more likely to have known a cancer survivor than children and young adolescents.

Second, support during diagnosis and treatment seemed to play a role in participants’ subsequent disclosure decisions. Participants who described receiving exceptional support from family, close friends, and even hospital staff also reported more comfort with disclosure and openness with their cancer history. Greater support during diagnosis and treatment likely lessened survivors’ worries about unwanted reactions from others to their disclosure, allowing them to establish a comfort with disclosure. The level of support that participants who were not as comfortable with disclosure received versus participants who received more support is unclear from the interviews.

Third, participants’ experiences with other cancer survivors and children with serious illnesses influenced their comfort with or perspective on disclosure. Some participants found it easiest to share their cancer history with children who had also faced serious illnesses. Other participants noted that events like cancer camp and cancer survivor scholarship luncheons allowed them to interact with other young cancer survivors, which changed their perspective on being a cancer survivor and on sharing their cancer identity with others.

Fourth, people often asked questions about participants’ physical changes, which led to disclosure of their cancer history. Participants noted the importance of the relationship between how one looks and how one is perceived. For participants who had no visible representations of their cancer, people were often surprised to learn about their cancer history. Participants who showed visible signs of their cancer experience, such as short hair, expressed that people treated them differently from when they didn’t show visible signs of their cancer. Participants also expressed how their college peers were unable to comprehend late effects, such as fatigue, and how this made survivors feel disconnected from their peers.

Fifth, survivors gave different definitions of “cancer survivor.” Some felt strongly about the distinction between “patient” and “survivor,” which influenced their perceptions of themselves and their comfort with disclosure. Other participants felt that a person is a cancer survivor from the time of diagnosis until death. All of the participants identified as a cancer
survivor. Some participants described being proud of their cancer survivor identity, while others expressed difficulty accepting the positive connotations of a cancer survivor identity.

Sixth, participants expressed different levels of connectedness to their college peers. One participant expressed feeling rejected by her college peers, yet noted that she couldn’t blame them, but instead, the college atmosphere. Other participants felt equal with their college peers and mentioned feelings of being in the “same boat.” Other participants expressed having a different life perspective from their college peers and an aversion to perceived college lifestyle norms, such as drinking and partying.

A possible application of these results is to develop a belongingness intervention for cancer survivors who are in college and who express a lack of belongingness. For example, Walton and Cohen (2007) created, conducted, and tested a belongingness intervention with Black and White first-year college students. Through survey results and quotes from upperclassmen, participants learned that all upperclassmen, regardless of race, had worried during their first year of college about whether their peers accepted them and that this worry lessened over time. This message was meant to normalize worries about belongingness and to demonstrate that students’ experiences were temporary, not permanent. Next, participants were asked to give a written and video-recorded testimonial drawing from their own experiences to relate to changing levels of worry over acceptance as college progresses, which was modeled in the intervention by upperclassmen. Black students in the treatment condition had better academic performance than Black students campus-wide, higher self-perceived potential to succeed in college versus the other treatment conditions (i.e., White control, White intervention, Black control), and maintained a sense of academic fit regardless of the level of adversity that they faced on a daily basis (Walton & Cohen, 2007). The results of Walton and Cohen’s (2007) belongingness intervention are impressive considering its simplicity. So, is the social stigma faced by cancer survivors in college sufficiently similar to that of Black college students for a belongingness intervention to induce the same positive effects?

Finally, participants offered advice to other young cancer survivors about disclosure. This advice provides insight into their concerns about disclosure. For example, participants suggested disclosing only when ready and comfortable, using disclosure to promote awareness of young cancer survivors, to create positive experiences, and to connect with
other people. They also offered advice on how to determine if people were worthy of friendship.

The interplay of disclosure, cancer-survivor-identity development, and belongingness is likely to influence health and academic outcomes. Practically, participants described instances when they disclosed their cancer history to obtain an accommodation or assistance, either from faculty members or their peers. In contrast, one participant described how her embarrassment about her cancer experience caused her to remove her hearing aids, which likely caused academic difficulties and possibly worsened her hearing. Additionally, considering the findings of past research, underlying psychological benefits may also be related to participants’ experiences of disclosure. Whether disclosure and cancer-survivor-identity development are beneficial or harmful seems to depend on the person’s positive and negative perceptions of the condition. Often, these perceptions are shaped by early disclosure experiences, proximity to and impressions of other people with the same condition, and beliefs about the cause(s) of the illness.

LIMITATIONS AND FUTURE DIRECTIONS

Selection bias is a Catch-22 of most disclosure-related studies. Specifically for this study, cancer survivors who were informed about the study but were uncomfortable discussing their cancer history were unlikely to participate. Conversely, the cancer survivors who did participate in this study were at least somewhat comfortable discussing their cancer history. One participant stated that Spanish was his preferred language, yet was capable and willing to conduct the interview in English. Conducting the interview in English instead of his preferred language might have limited his ability to use the best words to describe his thoughts and feelings. Future studies should consider replicating this study in different languages.

Unlike previous studies on cancer survivor identity, 100% of the participants in this study identified as a cancer survivor. This difference maybe an artifact of the questions asked. In the previous studies described in the introduction, participants were given a variety of labels from which to choose (e.g., survivor, victim, patient). In this study, participants were specifically asked if they identified as a cancer survivor. Therefore, results cannot be compared. Furthermore, the endorsement of the label “cancer survivor” by all participants is
an additional indicator of selection bias. Conversely, this finding may be a genuine representation of a increase in popularity of the label “cancer survivor” among those who have had cancer.

Additionally, this study has yet to reach information saturation, which means that the results presented here are likely incomplete. Recruitment was not exhaustive; only survivors who followed certain cancer- and college-related webpages on social media or visited one of the venues where this study was advertised knew of this study. Relative to the recruitment area (i.e., the United States), there is very little geographic diversity within the current sample, which limits the generalizability of the results. In addition, most of the participants in this study were leukemia or lymphoma survivors and either Caucasian or Hispanic/Latino. Participants from more diverse backgrounds (e.g., cancer type, race and ethnicity) would likely change the results of the study. For example, a survivor of bone cancer who had to have an amputation might have experienced disclosure differently. Similarly, certain cultures have varied beliefs about cancer that might influence a cancer survivor’s perceptions of his or her cancer, cancer survivorship, and disclosure. Furthermore, disclosure experiences might be different for women and men. Disclosure might also depend on students’ year in school and their living situation and proximity to other college students (e.g., living at home and commuting to school, living in the dorms, living in a fraternity or sorority house). The current sample was too small to examine these differences. Future analyses, however, should consider these possibilities. Furthermore, this study was primarily interested in the disclosure experiences of cancer survivors who are in college. The disclosure experiences of cancer survivors who are entering the work force or are at different periods in their lives should also be examined.

Future directions include recruiting more participants in order to reach information saturation and to revisit data analysis. Preliminary findings suggest several testable hypotheses for future research. The benefits and detriments of different levels of disclosure are important areas to explore in depth. Final findings will have the potential to inform the development of a needed measure of cancer-related disclosure and will provide insights into targeted intervention development.
REFERENCES


APPENDIX A

RECRUITMENT FLYER
young adult cancer survivors have a unique college experience and now have a special opportunity to help other young cancer survivors

new research study explores the young adult cancer experience and the sharing of his/her cancer history with others while in college

volunteers needed for a 1 – 2 hour interview via video chat conducted conveniently from anywhere and privately one-on-one

all information is kept confidential

nationwide search for young cancer survivors in college currently enrolled undergraduate minimum 18 years-of-age history of cancer contact for more information or to volunteer cancerdisclosurestudy@gmail.com
APPENDIX B

RECRUITMENT E-MAIL
Dear [student’s name],

Tonya Pan, a master’s student in the Department of Psychology at San Diego State University, would like to invite you to participate in a research study investigating young cancer survivors’ disclosure experiences (i.e., telling someone else about your cancer experience).

The study consists of one interview, which is expected to take between one to two hours to complete. The interview will be conducted over video chat (i.e., Skype or Google Video Chat), allowing you to complete the interview wherever is convenient for you. During the interview you will be asked a variety of questions about your cancer experience and times you have shared (e.g., talked, written, and/or publically spoken about) your experience with others.

Your participation is completely voluntary. To maintain confidentiality, all identifying information will be stored separately from your interview answers on a password-protected computer. Although you are an American Cancer Society Young Cancer Survivor Scholarship recipient, you should not feel pressured to participate in this research study. Your relationship with the American Cancer Society will be in no way affected by your decision to participate. The information you provide during the research interview will remain confidential and will not be shared with the American Cancer Society Young Cancer Survivor Scholarship Program. Your decision to participate in this study and/or the information you provide during the study will in no way affect your scholarship funding or renewal. If you do not wish to participate in this research study, please do not hesitate to decline.

If you would like to participate in this study, please contact Tonya Pan as soon as possible to schedule an interview. Tonya’s contact information has been provided below. E-mail is the preferred means of contact.

E-mail: CancerDisclosureStudy@gmail.com
Telephone: (619) 594-0447

This is a unique, non-transferable invitation; please do not forward this e-mail on to others.

Sincerely,

David Saunders, M. Ed.
American Cancer Society
Director, Mission Delivery
APPENDIX C

CONSENT DOCUMENT
San Diego State University
Consent to Act as a Research Subject

Disclosure Experiences of College Student Survivors of Pediatric Cancers

You are being asked to participate in a research study. Before you give your consent to volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators: Tonya M. Pan, B.A., and Vanessa Malcarne, Ph.D., Department of Psychology, San Diego State University.

Purpose of the Study: This study is designed as an exploratory investigation into the disclosure experiences of college students who are survivors of pediatric cancers. The research team would like to ask you to participate in an interview in which you will be asked to answer approximately 60 questions related to your cancer experience and talking about your cancer experience with others. The research team will be asking up to 30 college students, who are also cancer survivors to participate in this study. You have been asked to participate in this study because you are believed to be a college student, have a history of a pediatric cancer, and are age 18 or older.

Description of the Study: You will be participating in an interview in which you will be asked questions about your cancer experience and times you have shared information about your cancer experience with others. The research topic can be viewed as sensitive. The interview will take approximately 1 to 2 hours to complete. The interview will take place via video chat (i.e., Skype or Google Video Chat). You can be wherever you like for this interview (e.g., your dorm room, at home, on campus, in an office); however, the research team asks that the chosen location be a quiet place where you will not be disturbed for the duration of the interview. The interviewer will conduct the interview alone in a private, locked office at San Diego State University.

The interview will be audio recorded so that your comments can be optimally incorporated into the exploratory research investigation. If you are not willing to have your comments recorded, you should not accept this invitation to participate in the interview. If during the interview, you decide that you are no longer comfortable being recorded, you will not be eligible to continue taking part in this study. This is because the researcher needs to have an accurate recording of your comments. Your interview will be transcribed for research and the research team will have access. Your name and any other identifiable information will not be included in any of the transcriptions.

What is Experimental in this Study: None of the procedures or questionnaires used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.
Risks or Discomforts: There is potential risk for boredom and fatigue, so you will be allowed to take breaks as needed. There is also a potential risk for emotional distress when discussing issues related to your cancer experience. If you begin to feel uncomfortable, you may discontinue participation, either temporarily or permanently. Should you feel emotional distress, please contact Dr. Vanessa Malcarne (telephone: 619-594-6495; email: vmalcarne@mail.sdsu.edu) to receive a referral for psychological services. Dr. Malcarne is the supervising faculty member on this project, a professor of psychology, and a clinical supervisor at the SDSU mental health clinic. Dr. Malcarne will not be paid for any clinical services associated with this study.

Benefits of the Study: There may or may not be any direct benefit to you from participating in this study. The investigator, however, may learn more about the disclosure experiences of young cancer survivors, which may lead to future intervention research that may provide benefits for you, your family, other young cancer survivors, and society. I cannot guarantee, however, that you will receive any benefits from participating in this study.

Confidentiality: Computerized personal identifiable data (name, email address, and/or Skype username) will be stored in a separate, password-protected database. Your personal identifiable information will only be used to contact you to schedule an interview, to conduct the interview, and to notify you about the results of the study (if you requests notification), and will not be linked to your responses to the interview questions. Audio recordings of each interview will be turned into written transcripts for data analysis. Once all of the interviews have been transcribed, the audio recordings will be erased. All study materials will be kept in a locked office in a San Diego State University building with limited public access. You will not have an opportunity to review the recordings prior to publication. Research records will be kept confidential to the extent allowed by law.

The only time I would need to break confidentiality is if during a Skype session/Google Video Chat I see or hear something that would create reasonable suspicion that abuse or illegal activity is happening; I would also have to make a report to law enforcement.

Incentives to Participate: You will not be paid to participate in this study.

Costs and/or Compensation for Participation: There are no direct costs associated with participation in this study. (Standard Internet rates may apply.)

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with San Diego State University or the American Cancer Society. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed.

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact Tonya Pan (telephone: 619-594-0447; email: CancerDisclosureStudy@gmail.com). If you have any questions about your rights as a participant in this study, you may contact the Division of Research Affairs San Diego State University (telephone: 619-594-6622; email: irb@mail.sdsu.edu).

Consent to Participate: The San Diego State University Institutional Review Board has approved this consent form, as signified by the Board's stamp. The consent form must be
reviewed annually and expires on the date indicated on the stamp. Your consent is indicated by your participation in the study.

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<tr>
<th>SAN DIEGO STATE UNIVERSITY</th>
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<td>Approval Expires: 2/13/14 Revised: 5/15/2013</td>
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<td>Study Number: 1139087</td>
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APPENDIX D

INTERVIEW PROTOCOL
Interview Protocol

I. Thank you and introductions
II. Consenting process
   a. Would you like a signed copy of the consent document? [If so, provide instructions.]
III. Instructions and overview
   a. We are recording and the interview will be transcribed, so please speak clearly and do your best to fully express yourself. The recording will not capture your facial expressions and gestures, so it is important that you verbally express your answers.

Note: Please be open and honest in answering the following questions. Your answers are an important component to understanding the disclosure experiences of young cancer survivors. If you having difficulties in certain areas, others probably are as well. However, you don’t have to answer any question that makes you feel uncomfortable. It is perfectly fine to say that you would rather not answer a question, and we will skip it. Also, as we are going through the interview, if you think of something you would like to add to a previous question, please feel free to do so. Some of the questions are slightly repetitive. If you can’t think of anything new to add to your previous answer, that’s okay.

1. [If not known from e-mail conversation] Where did you hear about this study?

Cancer Experience and Demographics
2. Please state your gender for the recording.
3. How old are you? What is your date of birth?
4. Where were you born?
   a. [If outside of the US] How old were you when you can to the United States?
5. How would you describe your race or ethnicity?
6. What is your preferred language?
7. Do you have any siblings?
8. What type of cancer did you have?
9. What was the stage of your cancer?
10. When were you diagnosed?
11. How old were you when you were diagnosed?
   a. If the participant was diagnosed under the age of five, explain that some of the questions might not fully apply to them, but ask them answer them as best as they can or explain why such question doesn’t apply to them.
12. What grade were you in when you were diagnosed?
13. Where did you get your cancer-related medical treatment?
14. What type of treatment did you undergo (chemotherapy, radiation, surgery and/or other)?
15. How long were you in treatment?
16. Did you ever see a counselor, therapist, or psychologist for reasons related to your cancer experience?
17. Do you currently see a medical professional for follow-up related to your cancer treatment? If so, how often?
18. What type of physical changes did you have due to your cancer treatment (e.g., hair loss, scars, limb loss, weight change)?
   a. Were these changes temporary or permanent?
      1. How long did [each change in appearance] last?
19. Do you currently suffer from any late effects due to your cancer treatment (e.g., heart or lung problems, cognitive or memory problems, joint or bone problems)?
20. How much did your cancer experience disrupt your life?
21. How would you rate your current physical health status?
22. How would you rate your current psychological/mental health status?

*If diagnosed under the age of five, ask these questions:*

23. What do you remember about your diagnosis and treatment?
   a. If nothing, ask when their parents told them that they had had cancer.
24. Did your parents talk to you about your experience during and after your treatment was completed?

*Experience with Cancer (Pre-diagnosis)*

25. Before you were diagnosed did you know anyone who had had cancer?
   a. If yes, how did you find out that they had cancer? Please be specific.
   b. How close were you to this person?
26. What did you know about cancer before you were diagnosed?

*Diagnosis, First Disclosure Experiences, and Friendships/Social Support*

27. Can you walk me through how you were diagnosed? What types of diagnostic tests were used?
28. What events immediately followed your diagnosis (e.g., did you start treatment right away, did you go to school the next day, were you admitted to the hospital)?
29. Who was with you when you were diagnosed?
30. Immediately following your diagnosis, can you walk me through how you (or your parents) told people about your diagnosis? Please give specifics (e.g., over text messages, in person, on myspace or facebook).
31. Do you remember the very first time you told someone about your diagnosis?
   a. Who did you tell?
   b. Where were you?
   c. How did you tell them? Please provide specifics.
   d. Do you remember how they reacted?
   e. What kind of emotions were you feeling during this interaction?
32. Did you have a best friend around the time when you were diagnosed? If so, did you tell your best friend? How?
33. Around the time of your diagnosis, how did the majority of people find out about your diagnosis (e.g., your parents told them, you told them, your teachers/coaches told your classmates/teammates)?
   a. Who was told (e.g., classmates, teachers, school administrators, family members, family friends, other friends)?
b. Were you comfortable with how people found out about your diagnosis? If not, how would you have liked people to find out instead?
c. Before you went to college to whom did you personally disclose?
   i. Can you describe your experiences of telling people you have had cancer?
   ii. How did you tell people? Can you give specifics (e-mail, private conversation, in a group setting, etc.)?
   iii. How did they react?
      1. Please elaborate and give specific examples.
d. Before you went to college to whom did you choose not to disclose?
   i. Why or why not?

34. Around the time of your diagnosis and during treatment, what were your reasons for telling people about diagnosis?
35. In general, how did people treat you while you were going through treatment?
36. In general, how much would you say your cancer experience has impacted your life?

Cancer and School
37. In what city, state, and country were you K-12 schools located?
38. Did you have to miss a lot of school during your cancer treatment?
   a. How much time, in total, would you estimate you missed due to your cancer treatment and cancer-related sick days?
   b. [If a significant amount of time was missed]:
      i. How did you make up the time that you missed?
      ii. How did you feel when you came back to school?
      iii. How did your classmates treat you when you returned to school?
      iv. How did your teachers and administrators treat you when you returned to school?
39. Did anyone that you were close to before your diagnosis become distant after your diagnosis? If so, why do you think they did that?

College (present-day)
40. What year are you in school?
41. What college or university are you attending?
42. In your opinion, is it a small, medium, or large school?
43. Did you have to move to attend college?
   a. How far are you from home? (options in miles: 25, 50, 100, 150, 300, 600, 1200, 2400+) Examples: California Coastline: ~840 mi. Across USA (Augusta, ME to Los Angeles, CA): ~3300 mi.
   b. [If did move away to school] Where are you living (e.g., dorm, apartment, house)? With whom are you living? Did you know your roommates before you moved in?
   c. [If did not move away to school] Are you living at home or on your own? With whom are you living?
44. Are you still in regular contact with people you knew before you went to college (e.g., classmates, people from church)?
45. Are you in regular contact with your family?
46. Who would you consider to be your main social support or go-to person for support?
    If you felt like you needed to talk to someone, whom would you call?
47. In general, how do you feel about your cancer experience today?
48. Do you identify as a cancer survivor?
49. When did you decide or start to feel like you were a cancer survivor?
50. The National Cancer Institute defines a person as a cancer survivor from the time of
diagnosis until death. What do you think of this definition?
51. How has your experience with cancer changed how you think about yourself?
52. How do you think others perceive young cancer survivors?

Adjustment to College
53. How would you say you have adjusted academically to college? Are you doing well
in school?
54. How would you say you have adjusted socially to college? Are you doing okay with
making new friends? Are you happy with your social life so far? Are you involved
with any campus activities?
55. How would you say you have adjusted to college in general? In general, are you
satisfied with your college experience so far?
56. If applicable, how have you adjusted to being away from home?

College: Disclosure, Social Support, and Social Constraints
57. Please tell me about your experience of making new friends in college. Has it been
tough?
58. How do you feel about your peers?
59. How do you feel about your peers in comparison to yourself?
60. Before you went to college or after arriving at college did you think about whether
you wanted to tell people about your cancer history or not?
61. Since starting college, do you remember the first time you told someone about your
cancer experience?
    a. Who did you tell?
    b. How long ago was this?
    c. How did you tell them? Please provide specifics.
    d. Do you remember how they reacted?
    e. What kind of emotions were you feeling during this interaction?
    f. How did you feel after you told this person about your cancer history?
    g. How was this experience different from the very first time you told someone
about your cancer experience?
        i. Was it more or less difficult or about the same?
        ii. Why do you think that was the case?
62. Since starting college, have you told other people about your cancer experience? Why
or why not? Can you share any examples?
63. Can you tell me about the people you have told vs. not?
64. What are the main characteristics of someone who you would typically decide to tell
about your cancer experience as opposed to someone you wouldn’t tell?
65. Can you describe your experiences of telling people you have had cancer in college?
i. How have you initiated telling people in college about your cancer experience?
ii. Please give specifics (e-mail, private conversation, etc.).
iii. How did they react?
   1. Please elaborate and give specific examples.
iv. Have you found that some ways of telling people about your cancer experience work better than others in terms of getting people to respond in a way that your prefer?

66. Can you describe a time when you were hesitant to tell someone about your cancer experience?
67. Are there people with whom you want to share your cancer experience, but haven’t yet?
   a. If so, why?
68. Can you tell me about your most recent experience of tell someone about your cancer history?
69. Have you had any bad experiences sharing your cancer story?
   a. Why do you think this was the case?
   b. How did it make you feel?
   c. [If applicable] Did this or these experience(s) influence your decision to share your story with others?
70. What has been your best experience of sharing your cancer history?
   a. Why was this your best experience? What made it a good experience?
71. Have you told your professors you had cancer? Why or why not?
72. Currently, what are your reasons for telling people about your cancer history?
73. Currently, what are your reasons for not telling people about your cancer history?
74. How do you feel about your physical appearance today versus before you were diagnosed?
75. [If applicable] Has your change in appearance influenced your decision to tell people about your cancer experience?
   a. Do you think about your change in appearance [fill in participant-specific example] when you meet new people?
      1. Yes: Please expand. No: move on.
76. How do you feel around the people who know you had cancer?
77. Is there a difference between how you feel around the people who do not know you had cancer compared to the people who do know? If so, can you describe the difference?
78. Do people treat you differently (either good or bad) after they find out that you are a cancer survivor?
   a. If so, how?
79. How often do you think about your experience with cancer? [options: multiple times per day, once a day, weekly, monthly]
   a. What aspects of your cancer experience do you think about (e.g., going to the hospital or how you felt at the time)?
   b. When you think about your cancer experience do you talk about it?
      i. Why or why not?
      ii. To whom?
80. Have your feelings **about interacting with people** who either know or don’t know your cancer status changed over time [breakdown into periods]?
   i. Cancer diagnosis/treatment
   ii. Post-cancer/treatment completion
      1. High school if difference from ii
   iii. College/now

81. Have your feelings about **sharing your cancer experience** with others changed over time [breakdown into periods]?
   i. Cancer diagnosis/treatment
   ii. Post-cancer/treatment completion
      1. High school [if difference from ii]
   iii. College/now

82. In general, what challenges have you faced in regard to sharing your cancer experience with others?

83. In general, how do you feel when you share your cancer experience with others?

*Indirect Disclosure*

84. Have you ever mentioned anything related to your cancer experience on personal websites (e.g., facebook, twitter, a blog)?
   b. Openly or discreetly?
   c. Can you give an example?
   d. If so, why?

*Cancer Activism as a Motivation for Disclosure*

85. Have you been involved in any public awareness activities?
   a. Have you written about your cancer experience?
   b. Have you given speeches about your cancer experience?

*Final Thoughts*

86. What advice would you give to other young cancer survivors about sharing their cancer history?

87. Is there anything else that you would like to add regarding sharing your experience with others?

*Would you like to be notified about the results of the study?*

**Would you like to be contacted regarding future research opportunities?**
APPENDIX E

RESOURCE LIST
Resources for Young Cancer Survivors

Last updated: 3/5/2013

Social Support
American Cancer Society: www.cancer.org
Leukemia and Lymphoma Society:
http://www.lls.org/#/diseaseinformation/getinformationsupport/
LiveSTRONG Young Adult Alliance: http://livestrong.org/What-We-Do/Our-Actions/Programs-Partnerships/LIVESTRONG-Young-Adult-Alliance
http://livestrong.org/Get-Help/Find-More-Resources#/r/38
Cancer Planet Young Adult Community: http://www.planetcancer.org/

Education
ACSO Educational Resources: http://university.asco.org/focus-under-forty

Scholarships
(Application available in October)
Cancer for College: http://www.cancerforcollege.org/
WOKC Young Heroes Scholarship: http://www.wokc.org/YoungHeroesScholarships_16.aspx
National Collegiate Cancer Foundation: http://www.collegiatecancer.org/scholarships.html
(Due in May)
Friends of Scott: http://www.friendsofscott.org/scholarship.aspx
(Due in May)

Financial Assistance
Sam Fund: http://www.thesamfund.org/pages/grants.html

Activities
First Descents (outdoor adventures): http://firstdescents.org/