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Zpora R. Perry
Living in a Context of New
Knowledge: An Exploration
of the Experience of Young
Adults Transitioning from
Cancer Patient to Survivor

ABSTRACT

This is a qualitative study exploring the experience of young adults diagnosed with cancer as they transition from active treatment to full-time survivorship. The question on which this study is based is: What was this transition like logistically, emotionally, and relationally for those who have gone through it, in particular for young adults? This study was undertaken to identify if this was a significant transition and what support is needed through the process; implications for social work practice are included.

One-on-one interviews were conducted with twelve participants who were between the ages of 18 and 35, within two years of having finished treatment for cancer (chemotherapy, radiation, and/or surgery) and in remission. Questions were asked regarding the participants' experience of ending treatment, how this has affected them and their relationships, which aspects were most difficult, and where support would have been useful. Interviews were recorded, transcribed and then systematically organized into themes and sub-themes using the method of grounded theory.

The research finds the ending of treatment to be a significant transition. Participants reported unanticipated consequences of the ending of treatment, including strong emotions, fear of recurrence, continued physical effects, and difficulty integrating their experience. Participants suggested the utility of having support prior to and through this transition to normalize and ease the process.

LIVING IN A CONTEXT OF NEW KNOWLEDGE:
AN EXPLORATION OF THE EXPERIENCE OF YOUNG ADULTS
TRANSITIONING FROM CANCER PATIENT TO SURVIVOR

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2009

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CHAPTER I

INTRODUCTION

While there has been extensive research on the impact a cancer diagnosis has on a person, there is little discussion about the time after treatment has ended. Because traditional treatment ends when a person has gone into remission, it is considered a medical success and there is little perceived need for ongoing care. Perhaps there is a small ritual on the last day in the infusion room or a certificate from the radiation nurses, and you are then sent home to live your life as a healthy individual. However, this return to health is not a simple return to life pre-cancer, for the diagnosis and treatment have provided new knowledge that must then be integrated. This study focuses on that transition from cancer patient to cancer survivor and explores the subjective experience of young adults who are on such a journey. The question on which this study is based is: What was this transition like logistically, emotionally, and relationally for those who have gone through it, in particular for young adults?

Young adults occupy a unique space among cancer patients. They are no longer children who are under the care of their parents, and they are not yet at the age where many of their peers have faced life-threatening diseases. Additionally, they are often going through other transitions: With careers, relationships, family, etc. Cancer is layered on top of all of this and becomes interwoven with these other aspects of life. When treatment ends, the task is one of untangling and of sorting out the experience. Which parts of this experience does a person want to hold onto and which parts are no

longer useful? Where in a person's life is there room and support for these decisions to be made?

My informal hypothesis going into this study was that transitioning out of treatment is not a straightforward process. It is widely accepted that adjusting to the idea of being a cancer patient is not an easy process, particularly for someone in young adulthood. Additionally, having and surviving cancer is often life changing. It follows, then, that the transition out of active treatment and into full-time survivorship is a time potentially marked by the unease that comes with integration and adjustment. This study was undertaken to test this hypothesis and explore the experience of twelve young adults currently going through this transition.

The twelve participants were between the ages of nineteen and thirty-five and all had undergone traditional medical treatment for varied cancer diagnoses. They were all in remission at the time of the interview and within two years of having finished treatment, a period of time that has been identified by some studies as the time of most upheaval post-treatment. Everyone in the study participated without compensation, and many described feeling an imperative to contribute their experience to the greater body of knowledge on cancer survivorship in order to assist those coming after them in the process.

The title comes from an article on cancer survivorship that described the cancer survivor's time after treatment as "a life lived in a context of new knowledge" (Little, Paul, Jordens & Sayers, 2002, p. 176). This new knowledge is taken in and digested differently for each participant in this study, but the title seems apt as it alludes to the integration of an unexpected and jarring experience into a now-healthy life and leaves

what that will look like open to individual interpretation. My purpose in conducting this study was not to identify steps that each survivor goes through, but to determine if the process merits further discussion and how the social work and medical profession can be useful in navigating the transition.

My interest in this topic is personal as well as professional. I went through twenty-seven months of chemotherapy for lymphoma, finishing at age twenty-eight. My relationships with my family and friends as well as my self-image changed throughout this time. As I have grown physically stronger and moved further away from treatment, more questions and wonderings have arisen as I negotiate reclaiming my health without losing the lessons cancer has taught me. Because I was moving through this transition while studying social work, I have experimented with applying various theories to my situation as well as searching for scholarly work on the subject. This led me to choose this as a topic for my thesis, and the work that follows represents the study I undertook.

In working with my adviser, I have attempted to keep this project as scholarly as possible, in order to provide reliable findings. I hope that as a professional piece of work, my identity as a survivor will not muddy the validity of the study. Nonetheless, this has also been an important step in my journey and part of my healing process. My hope is that this will lend further credence to the study and to the importance of our role as social workers on this journey that does not end with the cessation of medical treatment.

CHAPTER II

LITERATURE REVIEW

In my exploration of the existing literature, I will first look at the idea of survivorship in general, then at the specific issues facing young adults. I will also look at any literature that explicitly examines the transitional time after someone finishes active treatment, and will survey gaps in the literature on this subject.

Survivorship

The term ‘survivor’ has gone through different definitions as the treatment for cancer has evolved. The concept of survivorship has only gained footing in the last 25 years as surviving a cancer diagnosis became more plausible. Survivor means different things to different people: For some it belongs to anyone who has been diagnosed with cancer, for others it is only bestowed to someone after he or she is in remission. For the purposes of this study, I will use Little, Paul, Jordens & Sayer’s definition (2002) of survivorship as, “living at any time after diagnosis and treatment have finished apparently free of cancer” (p. 171). This is not to belittle the importance of the active role that those going through treatment take in their healing, but to distinguish between those who are followed closely by health care professionals and those who are not. It is also to connote those whose primary identity is no longer pre-defined for them by their disease.

Little et al. (2002) write about the unique place the survivor occupies as they attempt to re-define their identity after a cancer diagnosis:

The survivor has as yet no specially defined status, no modes of performance that are socially validated. The survivor can therefore fit only into pre-existent and inadequate paradigms of the normal or the chronically ill, into metaphors of the victim or the hero. Survivorship is none of these. It is a category *sui generis*. It is a life lived in a context of new knowledge (p.176).

They note that one of the major challenges of dealing with such a disease is discontinuity of experience. They feel that people manage this by finding beliefs and external factors that anchor them and by “imbuing the experience with meaning and recognising the enlarged identity made possible by survival” (p.170). Clearly, this will look different for each person as they determine how best to make their own meaning. Brennan (2001) observes, “more than any other organism, human beings are self-regulating systems which have excelled at learning from experience” (p.7). From this perspective, survivorship is a time for people to allow for this self-regulation as they make meaning and take stock of how cancer has altered them. These less tangible tasks exist in the shadow of the concrete fear of recurrence.

Koocher and O'Malley (1981) use an ancient fable to vividly illustrate this shadow, which he terms the Damocles syndrome: Damocles was invited to a feast at which all manner of decadence and luxury was arrayed before him, yet when he looked up “he discovered he was seated directly beneath a naked sword suspended above his head by a single horsehair” (p. xvii). So the dilemma of a survivor exists: How to enjoy life and the wondrousness it offers without ignoring the specter of danger. For some, this may lead to a greater appreciation of life, as was found in studies that have compared cancer patients with those who had never had a terminal diagnosis (Cella & Tross, 1986). If not a greater appreciation, likely greater reflection will result: reevaluation of one's

priorities, an accounting of what and who is important, an increased curiosity in the age-old question of the meaning of life.

The time of transition to survivorship is a time in which people are discovering how they will live with a heightened awareness of the uncertainty of life. For an elderly person who has lived a full life, mortality is likely more of a familiar concept. Their process will look different than that of a young person who has not yet had to face the possibility of dying, and who is imagining their whole life ahead of them. Some researchers have become aware of this dissimilarity and begun looking specifically at young adult survivors.

Young Adults

As a group, the phrase ‘young adult’ covers a wide range of years, from ages 18-35. Developmentally, however, there are similarities and generalizations that can be made. Young adults are often still in school, and are surrounded by a healthy peer group. They are less likely to be financially secure and more likely to have issues with insurance and employment. Duffy-Lind, O’Holleran, Healey, Vettese, Diller & Park did a study to look at the continuity of care for adolescents and young adults and their emotional, physical, and social issues as they transitioned out of treatment (2006). Their study revealed concerns among this population about being different from their peers, worries about insurance, fears about no longer being closely followed by their doctors, and emotions ranging from elation to abandonment. This is echoed in the recommendations put forth in the Report of the Adolescent and Young Adult Progress Review Group (AYA PRG) (2006) which found needs specific to young adult cancer survivors in the arena of intellectual (concrete information regarding their disease), interpersonal (struggles with

isolation or reentry into peer group after an absence due to disease), emotional (both positive changes and adjustment struggles), practical (insurance and financial difficulties), and existential/spiritual (uncertainty).

What is clear in the literature is that the various logistical and physical effects of cancer treatment and their emotional and psychosocial sequelae have ramifications that are unique to young adults. For example, Zebrack, Casillas, Nohr, Adams & Zeltzer (2004) write about fertility issues for young adults who have survived childhood cancer. He found that while young adults who have survived cancer may have more confidence in themselves as a future parent, if fertility is threatened because of treatment, “a perceived loss of opportunity for parenthood may be devastating to self-esteem and potentially damaging to marital or other intimate relationships” (p.696). This two-sides-of-the-same-coin approach is proposed as particular to young adults who have dealt with cancer: On the one hand they have more fear about the future and less confidence in their bodies as a result of the betrayal of cancer – somehow their young, healthy body allowed in a foreign invader. On the other hand they have “more appreciation of their current and future success related to having overcome a dreaded disease” as well as “greater...clarity about a philosophy and outlook on life” (Zebrack & Chesler, 2001, p. 253).

With regard to this issue of life outlook, the study of the AYA PRG (2006) found that young adults reported, “while uncertainty can be a source of distress, it also can be a catalyst for personal growth, a deepened appreciation for life, greater awareness of life purpose, development of confidence and resilience, and optimism” (Appendix B, p. 42). Bellizzi, Miller, Arora & Rowland (2007) also found that young adults were experiencing these things, in contrast with older adults, who reported less impact, either negative or

positive, on their lives. Similarly, another study investigating quality of life in long-term cancer survivors identified four themes: Personal Growth, That's Life, Relinquishing Control, and Resentment. These results, mirroring those of previously cited studies, found that older people were more likely to respond along the "That's Life" theme, while younger survivors named "Personal Growth" as a theme more often (Foley, Farmer, Petronis, Smith, McGraw, Smith, Carver & Avis, 2006). The explanation for this could be that older people have had more life events from which to draw and assess impact and therefore approach their illnesses with more resigned attitudes. Perhaps young adults see a greater imperative to learn from their experience because of the potential for a number of years of life ahead of them. In either case, it is evidence that young adults experience cancer differently and therefore experience cancer survivorship uniquely as well.

While it would be impossible to separate the logistical from the psychosocial consequences, as the former often gives rise to the latter, it is worthwhile to look at the specific logistical challenges young adults face and what ramifications these might have. In a survey of oncology social workers who have experience advocating for young adult survivors, the most common themes were worries about health insurance, concerns about fertility, fears about how cancer will affect their current and future intimate relationships, and becoming dependent on others (Zebrack & Walsh-Burke, 2004). The authors note that these patients will be faced with how to manage long-term care and how to ensure health care coverage to pay for it. They cite helpful online tools such as the Cancer Survival Toolbox and the need to tailor these to meet the needs of a younger clientele. This is echoed in the recommendations of the AYA PRG which calls for a way to ensure "excellence in service delivery across the cancer control continuum" and to "strengthen

and promote advocacy and support” of young adults dealing with cancer (2006, p.iii). If these logistical needs are not met, the psychological needs will only become greater.

The AYA PRG is one of the few places in the literature on this subject where the impact of culture and race on these logistical and psychological needs are addressed. They hold that to understand this population’s needs and risks “necessitates an awareness of the strong, often covert influences of culture, race/ethnicity, and socioeconomic status in shaping reactions and responses to health problems” and remind us that “neither equitable nor adequate access to quality cancer care is ensured for everyone in today’s health care environment” (2006, Appendix B, p.43). The circumstances under which cancer treatment is administered sets the stage for a young person’s experience of survivorship.

Koocher’s studies focus on children, who, like young adults, have most of their lives ahead of them. Their lives will undoubtedly be shaped in some way by their diseases, perhaps with increased gratitude for life and accelerated personal growth, but also with “a conscious or subliminal awareness that a substantial risk, much like the sword of Damocles, hangs over their futures” (1981, p.xviii). This dawning recognition of a new reality seems to be most acute for young people in the period of time directly after treatment.

Transition

It is widely accepted that transitions are the times in our lives when we most often stumble. It is perhaps counter-intuitive to imagine the transition from sick to well as being hard, but just like any other shift in identity, adjustments are called for. Mullan (1985) defined three stages, or “seasons” in cancer survival: “Acute stage” during

treatment (characterized by fear and anxiety), followed by “extended survival” (characterized by watchful waiting), and finally, “permanent survival”. It is between the acute and extended seasons that I propose the greatest transition occurs. Cella et al. found that the time of greatest “psychological distress and psychosocial disruption” occurred within the first two years off of treatment, and lessened with time (1986, p. 616).

Allen, Savadatti, & Levy (2008) studied this transition time for breast cancer patients who were within one year of having finished active treatment. They found that this was a dynamic time in women’s mental and emotional lives. Their findings supported the idea that the completion of treatment is “in many ways a welcome milestone”, and also “a time of great hardship, uncertainty, and isolation for many women” (p. 6). Are there ways to mitigate the hardships of this time? The authors conclude that developing interventions specifically aimed at supporting the physical, emotional, and social health of those going through this transition is a necessary part of cancer treatment. Another study stresses the need for a clear Survivorship Care Plan for each patient to have when they complete treatment (Hewitt, Greenfield & Stovall, 2006).

The idea that those in this period need support is further explored by the research of Carpenter, Morrow & Schmale (1989), whose findings suggest that patients became dependent on their physicians for comfort and have a difficult time adjusting to less frequent medical visits at the end of treatment and when this consistent support is subsequently withdrawn. The logical implication is that other forms of support are needed. Black (1989) suggests that social workers, as agents of empowerment, are well placed to offer this kind of intervention. The role called for is one of empowering

survivors and their families to face the uncertainty they are left with after treatment, which can be a major source of stress. Conversely, another study found no difference between those who accessed psychosocial interventions after treatment and those who did not (Fritz, Williams & Amylon, 1988). This could either be an anomaly, or may suggest that this is a more individual process, and therefore indicating no one solution.

Arnold (1999) conducted a qualitative study on the end of treatment as a crisis, finding that from diagnosis through survivorship, cancer is a series of crises. The end of treatment crisis is precipitated by the shift from a proactive approach to cancer with traditional treatment to the more helpless uncertainty of having finished treatment. Additionally, she found that with many patients, there was a discrepancy between their loved ones' desire for a return to normalcy and the patients' ongoing difficult adjustment. In addition to their loved ones, she suggests that there is perhaps a societal value placed on coming through difficult times easily, adding additional pressure to recover quickly without psychological distress. These external pressures conflict with the internal reality of confusion, and therefore a new sense of psychological balance must be discovered, as found in Arnold's and other research studies (Ward, Viergutz, Tormey, DeMuth, & Paulen, 1992, Little et al., 2002). Arnold cautions, "Rather than turning patients loose into what one might believe is a world of newfound freedom from the limitations of cancer treatment, one must consider that the cessation of treatment is also a period that breeds fear and uncertainty" (1999, p. 34). Ward et al. propose looking at the cancer journey through the lens of crisis theory, and see the resolution of it as

...a process characterized by time- and event-related plateaus of equilibrium. One such plateau may be achieved during [chemo- or radio-] therapy. And for some... the termination of therapy may shatter this tentative equilibrium. Thus, the theory

may help explain the apparent paradox of [people] who are upset when a noxious experience...is over (p.362).

For young adults, whose considerations include developmental milestones like having children, starting long-term intimate relationships, and choosing a career path, the reasons for this paradox become more clear: Normal life decisions and processes are now given a new dimension with the reality of being a cancer survivor.

Few of these studies address issues of diversity and how someone's environment might affect their psychological state. Some differentiate by gender (Kazak, Christaks, Alderfer & Coiro, 1994) and ethnicity (Foley, Farmer, Petronis, Smith, McGraw, Smith, Carver & Avis, 2006) and place the survivor within the greater context of the systems they encounter, but most do not examine this in depth, investigating the complex interplay of cultural beliefs as they relate to cancer, and many simply do not address it at all.

Summary

Recently, the literature has begun to look more closely at both survivorship as a part of the cancer process, and at the unique needs of the young adult cancer population in survivorship. There are studies that conclude that struggles do not end with the completion of treatment and that cancer has long lasting effects, both positive and negative, on people who have carried this diagnosis. Young adults are more likely to experience their cancer journey as a life-changing experience with great positive effects, as well as the more obvious negative ones. The transition period, within 24 months after finishing treatment, is less well represented in the literature, but according to the authors

that have studied this time, it is a fertile one for emotional and social upheaval. There is a dearth of literature on the transition for young adults. As researchers have proposed the importance of this transition and the growing population of young adult survivors, it follows that ongoing research is needed. Studying this period as it specifically affects people aged 18-35 should yield useful information to formulating programs with interventions that target this age group at this period in their life.

I will be conducting a qualitative research study on young adults who fall within this age range to obtain information on their subjective experience. Most of the studies that used a pre-determined instrument to conduct a quantitative study recommended future directions for research in the realm of qualitative research in order to understand a less well-studied phenomenon. My study will begin to explore the questions related to this transitional period: Is it different for young adults than for the older population of cancer survivors? What difficult experiences have people had that they were perhaps not expecting? How has this period impacted them in positive, life-altering ways? Are there experiences they are seeking extra support for from the medical and mental health profession?

Because of the nature of the study, I am not entering into it with a formal hypothesis. However, I do theorize that the research will uncover themes of personal growth and transformation as well as difficulties related to the paradox of a crisis associated with a seemingly positive life event, as well as the unique developmental stage young adults occupy.

CHAPTER III

METHODOLOGY

This study is an exploratory investigation into the experience of young adult cancer survivors in the transition from active treatment to full-time survivorship. It was designed to consider questions regarding their experiences of the ending of treatment and transitioning to life without treatment for cancer; what was helpful and what was lacking, how their experiences matched with that of their loved ones, and if they had any surprises or ambivalence related to the ending of treatment.

Formulation

There is little in the existing literature that specifically addresses this transition, and how it is navigated by young adults. As a response to this gap in cancer research, I chose to conduct a qualitative study to hear people's stories in their own words and to begin to identify areas of further investigation. Grounded theory was used to code the data, finding themes and concepts that were common across participants. The format was twelve one-on-one interviews in person or over the phone, lasting between forty-five minutes and one hour, which I then audio-recorded and subsequently transcribed.

Obtaining a sample

The sample consisted of twelve participants who volunteered their time to be a part of the study. The criteria to be included were as follows: Each participant had to be between the ages of 18-35, had to have received a cancer diagnosis and undergone traditional allopathic treatment (chemotherapy or radiation or surgery), had to be within

24 months of having finished this treatment, and had to be currently in remission.

Excluded from this sample were those people that were out of the age range, were still actively receiving treatment, or who had stopped treatment because of a terminal diagnosis.

There was a limited time-frame within which to conduct this study. Therefore, it was conducted with a convenience sample, and the bulk of the interviews were over the phone. Much of the survivorship support for young adults currently is online. Therefore, that was the primary method of recruitment. As a result, most participants lived at a distance from me, necessitating phone interviews. Snowball sampling was used, which also worked in a virtual fashion: Survivors who had seen the request for participants forwarded it to their survivor listserves and online groups.

Before beginning recruitment, I submitted a proposal to the Smith Human Subjects Review Board and received approval (see Appendix A for copy of this letter). A flyer was developed (see Appendix B) to introduce the study and provide inclusion criteria. This flyer was circulated locally to contacts at two major medical centers, a community cancer support center, and social work and public health programs at the local university. On the web, I contacted a woman who writes a daily blog about living with cancer as a young adult and was able to “guest blog” to explain the study and reasons for undertaking it. I also used an online networking group for young adult cancer survivors as a recruitment tool and contacted the director of I’m Too Young for This (i2y), a young adult cancer survivorship organization. In all cases, some version of the information on the flyer was provided, in expanded or condensed format, and interested participants were asked to contact the researcher by telephone or e-mail.

Once interested participants had made the first contact, I responded with their preferred method of communication (generally this was by e-mail) to administer a short survey to ensure they met criteria: Were they between the ages of 18 and 35? Had they been treated for cancer with chemotherapy, radiation and/or surgery? Were they within two years of having finished said treatment? Were they currently in remission? If they answered yes to all of these questions, I explained what participation would entail and provided information about confidentiality. Consent letters with detailed information about confidentiality and participants' rights were then distributed with self-addressed, stamped envelopes (see Appendix C for sample consent letter sent to potential participants). Upon receipt of the signed consent letters, I contacted participants to arrange a convenient meeting time in an appropriate location.

Confidentiality

In the consent letter, provisions for confidentiality were set forth for participants, and then followed to ensure appropriate and ethical treatment of the data. All identifying information was removed from data, and the researcher was the only handler of this information. Demographic information reported in the study was given as a whole, and names were not used. Participants were informed that their participation was completely voluntary and if they wished to withdraw their data from the study at any point before the report was written, their information would be promptly destroyed. Participants were also informed of potential harmful effects of being in the study, as interview questions could bring up painful feelings and difficult memories. Referral resources were included for each participant's use as needed. (See Appendix D for a copy of the national resources provided; as participants were from different regions, local resources varied.)

Participants

Participants recruited through the above process all fit within the criteria stated above. They ranged in age at time of interview from age nineteen to age thirty-four. Out of twelve participants, seven were female and five were male. Eleven participants identified as Caucasian and one person identified as African-American. All twelve participants reported their socio-economic status to be middle class. The length of time out of treatment ranged from seven months to nineteen months. Diagnoses included lymphoma and leukemia, brain cancer, breast cancer, sarcoma, and testicular cancer. All participants were in remission at the time of the interview. One participant has had a recurrence since that time and is currently undergoing chemotherapy.

Data Collection

Data was collected through one-on-one interviews (see Appendix E for interview guide). Three were done in person; nine were done over the phone. The first three interviews were recorded using a digital recorder and then transcribed. After those three, recording was done by computer software, which provided greater quality recording and ease of transcription. I did the transcription within three weeks of each interview.

Data Analysis

Data were analyzed according to the method put forth in grounded theory: Transcriptions were reviewed for recurring themes and sub-themes and grouped into codes. As I had done the transcription, I was familiar with the data and had ideas before formally creating codes. Rough ideas of codes were developed before review, and then transcriptions were reviewed and when these codes occurred, they were marked. After all data was reviewed once, codes were adjusted to be relevant to all the data they

addressed. Some themes were found to have enough similarities to others that they were placed under the same broad heading. Data were reviewed a second time to ensure validity of codes and to highlight quotations that exemplified each category.

Potential Biases

I am highly aware of my potential bias as a young adult cancer survivor and have been careful throughout the process to address the data as systematically and methodically as possible in order to minimize skewing the data and rendering the study invalid. Through consultation with my adviser, we have discussed the benefits and potential pitfalls of my bias and employed a checks and balances system to keep the research reliable.

CHAPTER IV

FINDINGS

The research attempted to collect data on the subjective experience of young adult cancer survivors as they moved from active treatment into full-time survivorship. Twelve interviews were conducted with young adults between the ages of 18-35 who had been diagnosed with cancer and undergone an allopathic treatment (chemotherapy, radiation, and/or surgery). All were in remission and within two years of having finished treatment.

In coding this data, I have attempted to find themes that are present through all twelve interviews. I have had some hesitancy with categorizing responses, as I have wanted to honor each participant's individual and nuanced process. With that in mind, however, there are some clear commonalities across the varied and unique experiences each person is living.

The majority of the participants described the transition time, particularly the several months directly after finishing treatment, as containing some unanticipated consequences, or an expectation (their own or an outside one) conflicting with their actual experience. Fear of recurrence or relapse was another overarching theme – both among those who had already relapsed at least once and those who had not. Another theme was the realization that the transition is an evolution and that the experiences change over time. Participants expressed a desire to get involved in the cancer community or described ways they had already done so. The effect of cancer on

individual identity and/or personal worldview was also a theme; as was the uniqueness of the participants' status as young adults, and for many, this contributed to some feelings of isolation and loneliness.

As I only interviewed people who were within two years of having finished treatment, most still felt that they were in the process of transitioning and were describing their present experience. Therefore they were very much *in* the process that D., a twenty-nine-year-old Hodgkin's survivor, described as:

kind of throwing a wrench into my plans and really like someone broke a glass on the floor and I'm now kind of putting the pieces together and putting them in the right order and making sure the colors match...

Interviews done in two more years would likely uncover different themes, as participants endorsed an ongoing evolution of their experience, and were able to identify ways their outlook had shifted as they move farther away from the ending of treatment.

Unanticipated Consequences

Broadly, this theme encompasses participants expressing that at least one part of the transition out of active treatment included something they were not prepared for. Out of twelve participants, ten people described being surprised at some aspect of this period. Of these ten, five endorsed unanticipated physical consequences (feeling that their energy and physical abilities did not come back right away) and seven endorsed emotional consequences (emotions that arose after treatment that were not present during treatment). Some of this surprise was in how long the effects lasted after treatment ended, and some of it was in experiencing the effects at all.

For most participants, this was a difficult thing to encounter because of their own expectations, expectations from their support system, or perceived societal

expectations. Most participants implied this conflict in their description, and for others it was more explicit. Intrapersonal, interpersonal, and society expectations are all represented within these responses.

Physical

Chemotherapy, surgery, and radiation are inarguably hard on the physical body. This is a well-known and much talked about fact. All participants described the rigors of these treatments: losing hair, low blood counts, extreme fatigue and nausea, burned skin, limited mobility after surgery, and general discomfort. The surprise was that after the treatment ended, in some cases, the physical effects remained. C., a thirty-one-year-old Hodgkin's survivor, said:

For me, in my mind, as soon as cancer was over I should be fine, that's it. But really it took me a lot longer just to get back to my normal strength levels than I had hoped. I had hoped it was a more immediate thing.

For C., his own expectations and wishes were that he would get back to normal levels right when treatment ended. Other participants reported that their oncologists had warned them that it would not be an immediate recovery, but they did not know just how long it would take. Some participants were surprised that did not feel they were back to pre-cancer energy and health and wondered if they ever would be. One reported, "it's like cancer aged my body ten years. I'm just not ready to accept that."

Emotional

The majority of participants (seven out of twelve) described unanticipated emotional consequences. Emotions experienced in the transition after treatment included feeling overwhelmed, scared, angry, uncertainty about reduced contact with their

physicians, and missing the interpersonal closeness with loved ones that occurred during treatment as well as the single-minded focus of the therapy. A sub-theme of this that arose in interviews was the difficulty of the participants' no longer feeling in control and having something to do to actively fight the disease.

A., a twenty-four-year-old Hodgkin's survivor, echoed the words of many in her characterization of the emotional consequences that came as a surprise:

...it was just like there was so much to focus on, and then once treatment is over, it was all gone. You know, immediately. It was just all done. So it was kind of – I think it was just a huge, *huge* shock that I could not have been less prepared for.

She also had an emotional reaction that felt so unexpected that she tried to push away what she was feeling:

Part of me was like 'the feelings you're having are ridiculous, think about what other people are going through', like suck it up, basically. And just kind of feeling like I didn't have the right to be – as weird as that sounds – I didn't have the right to be as emotionally screwed up as I felt, because what I had gone through was nothing compared to what other people were going through, and if they had gone through that, then I was clearly – or should be – strong enough to go through what I did.

A's sentiments are similar to those of other participants in that, without having gone through this experience before, she suggests, it would be difficult to prepare oneself for the emotions that accompany treatment ending. A's expectations did not include being shocked at the feelings accompanying treatment being over, and because of the shock, she attempted to deny her feelings of guilt and feeling unsettled. M., a twenty-eight-year-old testicular cancer survivor, was surprised at the lack of positive emotions, echoing the "should" of unmet expectations: "in some ways I felt it should have made me happier – the end of treatment and the low risk of recurrence. Like I felt it should have made me happier than I am". Another participant, B., a twenty-four-year-old sarcoma survivor,

describes a similar surprising experience, and reports that her lack of anticipation of these emotions made what she was feeling even more difficult:

Because I kind of expected that the active treatment stage would be the scariest and then after I was done I would just be...you know...glad it was over. But instead after it was done I was still really scared, and that actually seemed, for me, harder after I was done with active treatment.

B., along with most of the other participants who described emotional consequences (six out of seven) referred to her inability to be actively fighting the cancer with medication or radiation as creating feelings of helplessness that exacerbated their emotional responses.

She says:

after I was done then there was nothing I could do besides wait. Like I couldn't get radiation, or look up the best treatment because I was done. All I could do was...wait...for the three-month scans and you know, in the meantime think that I hear wheezing all the time.

M., a thirty-one-year-old breast cancer survivor, says:

I think the one thing that I wish I had known was that the transition might be the hard part. That it's easy to fight, and then when you're not fighting and you're not seeing a doctor every day and you're sort of floundering, that that is hard, but that's normal and that it gets better...I didn't get angry about it until well after it was over, and I think to know that it's normal to get angry is also helpful.

M.'s observations, along with echoing the relative ease of "fighting" versus "not fighting", brings up another sub-theme of these participants, which is the desire to have their experiences normalized, and to know they are not alone in their emotional responses. Without normalization, participants talked about feeling like they were "going crazy" and wondering "what's wrong with me?" A., Hodgkin's survivor, talked about going to see her physician after a month and the comfort this gave. She said it was "nice to hear reaffirmation of all my freaking out because nobody else could really – she clearly understood exactly what I was feeling." K., a thirty-four-year-old leukemia

survivor, describes similar relief at knowing she was not alone in her strong emotional response:

It hits you very hard when you're done because suddenly now you're healthy and now you have time to actually sit back and think about what you just went through and how in the world did I do it, and...wow. I can't imagine that I just did that, what I did. There's no time to think about it when you're in treatment, you're doing what you have to do to get by and doing what you have to do to be healthy. But after, the emotional aspect hits you. And no one talks about that. No one tells you that. Until you bring it up. And you ask like am I normal and they say 'oh yeah, yeah'. They don't tell you though.

N., an eighteen-year-old sarcoma survivor remembers that after treatment, "I kind of went like crazy". Unlike some of the others participants, however, his experience was normalized before he had it because of other survivors he had spoken to:

I've talked to a lot of other people that have had cancer and they go through the same thing, they don't know, as soon as they got done with treatment they're kind of like I don't know what to do now.

External Expectations

Most of these unanticipated consequences were a surprise because of intrapersonal expectations not being met. Others describe emotions related to expectations from others. K., leukemia survivor, reports:

The doctor releases you to go back and people automatically think you're done, you're better – you're cured, you're better! But now when you're finished is when you deal with all the emotional aspect of what you just went through.

A., Hodgkin's survivor, describes, "My entire life for the last more than six months has been week to week and now it's like – oh now you can make plans. It's like well wait a minute, wait a minute – I'm not ready!" N., a twenty-nine-year-old survivor of three different cancers, the most recent being breast, says, in describing her emotional response, "I think with my parents it's kind of like well you're fine now, you're ok, and we don't want to think about that at this point, it's too difficult". B., sarcoma survivor,

says “now it’s kind of expected that I should be moving on and getting on with my life” and described a general “pressure to be like a cheerful survivor who moves on so quickly, and I’m not sure where it comes from because it comes from so many places”, alluding to societal expectations that can at times conflict with the internal experience of survivors.

She also notices that:

Everyone’s always judging the people, like this is a good survivor, or this is a bad survivor, and this person has a good attitude and therefore will be fine, but this person, we don’t know why they’re so down about it.

At the time of the interviews, all ten participants who described unexpected physical or emotional effects had since had their experiences validated by a physician or another survivor, and wanted that information to be more widely known. Those participants who endorsed unanticipated consequences uniformly advised new patients going through this transition to “take it slow” and “don’t put any pressure to be better” and suggested that survivors “accept that you’re not [fine], and give yourself the time ‘til you are”. G., a thirty-year-old brain tumor survivor, referenced these unexpected consequences and advised others:

As time goes on, you know, you will get better and better, and...time does heal, mentally and physically and stuff like that so don’t get discouraged – you’ll come around. For me it took longer than I realized, so don’t think that it’s not going to happen. It will happen, just give it time.

Fear of Recurrence

Another theme was a fear of recurrence or relapse, which one participant described as “that dark cloud following you”. This worry ran throughout the interviews, both explicitly (fear of dying) and implicitly (difficulty not seeing physicians as regularly for reassurance). In some ways, this theme overlaps with the theme of unanticipated

emotional consequences, as survivors describe being surprised at how strong this fear is. B., sarcoma survivor, says: "I think the only surprise for me was how hard it was dealing with the fears involved with remission, or the fears of relapse, after you're done". Half of the participants (six out of twelve) described an increase in fear of recurrence since they finished treatment. One participant described a strong fear of recurrence that had remained unchanged since treatment. A smaller percentage (four out of twelve) describe a decreased fear of recurrence since finishing treatment, and one participant felt worry about relapse had not been a factor either during treatment or in the transition period.

For the six participants who considered recurrence to be something they worried about more since treatment, most attributed this to an increase in energy and decrease in the singular focus of treatment. B., sarcoma survivor, describes being in treatment as being "on auto-pilot" and others make note of the fact that you're "doing something" to keep the cancer away when you're getting treatment and that there is "some type of protection". A., Hodgkin's survivor explains it this way:

You know during chemo it was like oh well, we're killing it, you know like that's why I sit there for eight hours having chemicals pumped into my body – because it's being killed. And once treatment was over it was like well...are you sure? Are you sure it's all gone?

M., breast cancer survivor, says "you've been fighting and fighting and fighting for however many months and you're doing something every day" so that when you are done with the regular treatments, "you're like but I still want to be doing something, what can I do?"

Some participants talked about a change in the scope of outlook – from very short term during treatment to long term afterwards – as a factor in increased relapse thoughts.

K., leukemia survivor, explains “now, I think because I’m starting to feel better, my life is back to normal, I feel like it kind of hangs over my head that – oh, it could come back”. Others described a shift into a more diffuse focus with imagining how to remain cancer free. M., breast cancer survivor, says, “When I was going through active treatment, there was a specific enemy. You know, there was a single enemy to deal with then. Now there’s the unknown enemy, and in some ways that’s a little bit harder.” N., sarcoma survivor, echoes the idea of being disoriented by a less defined struggle, saying, “when I was on treatment, you know you already have it, you don’t have to worry about it coming back”. He has noticed that not doing treatment, “you’re kind of like lost – all you knew is the hospital and how to fight cancer, but now what do you do when you don’t have it anymore”, which is why thoughts of recurrence increase.

Another factor for many participants who noticed an increase in fears of recurrence was the decreased monitoring by medical professionals – oncologists and oncology nurses. Many reported wondering, “what’s going to happen?” “Who’s going to tell me I’m okay every week?” K., leukemia survivor, says:

There’s no transition! I feel like with the doctor he just kind of kicked us out like he doesn’t like us anymore! Cause he was like all of a sudden, I’m done, I’ll see ya and I was like whoah, I’ve seen you like every day.

J., twenty-seven-year-old Hodgkin’s survivor, likens it to “kind of like the first time you go off to college – like all right, you’re on your own now!” and notes that it is “a little bit scary” as it takes some time to be able to “resume your life after this huge tragic things that’s happened to you, and get back into the swing of things and get on with it”. These participants recall being asked about every cough, every bump, every energy fluctuation during treatment, and many describe the lack of this consistent monitoring by

a medical professional “disconcerting” and they are left to wonder on their own about whether any of these changes mean a recurrence.

Of the three people who felt they have had a decreased fear of recurrence since treatment ended, one had already relapsed twice and one had experienced three different types of malignancy at different times. The third felt he was “not one to dwell on what-ifs”. All three felt that a distance from hospitals and medical professionals allowed for a decrease in thinking about the cancer returning.

Impact of Cancer on Identity and/or Worldview

Whether undergirded by a fear of recurrence, an awareness of one’s own mortality, or an appreciation for loved ones, all participants (twelve out of twelve) discussed some change in their outlook on life or their identity, or both. Phrases to describe this included “more compassionate”, “willing to take a leap”, “greater appreciation” and “preciousness of life”. People describe the transition as a time to learn about these new parts of themselves and integrate them into their lives. D., Hodgkin’s survivor, says he has “become less selfish about me and cancer” and notices he has a:

sense of appreciation just for the here and now that I don’t think I had maybe a year or two earlier. I think this sense of being comfortable with how things are rather than putting things out there which only just causes more distress and more angst because of why can’t I do it and why can’t I...when you sort of wrestle with that it makes it more difficult to just sort of be content with what is.

N., sarcoma survivor, reports learning that “healthy is not something you can really choose” and the importance of staying close to loved ones. He reports that cancer treatment “was a pretty life changing experience. I think you grow up really quick.” C., Hodgkin’s survivor, reflects a similar shift in priorities:

Prior to cancer I was trying to do well in law school and trying to get a job and sort of caught up in that world – the world of trying to over-achieve and trying to do the best you can all the time and sometimes I would take my relationship with my friends or even my girlfriend, even my own family, for granted. I think after cancer I take a different approach now.

Participants reported both positive and negative changes. J., Hodgkin's survivor who went through one recurrence, says:

I definitely learned the hard way that anything can happen to you. Anything can happen to anybody, you know, nobody is protected, nobody is invincible. I don't feel like I have a negative outlook, but I'm definitely more cautious of being too optimistic, I guess. I just feel like if I get too positive or too sure that it's never gonna come back, that that's when I'll get blindsided again and it will come back.

She also notes:

I don't want to say I'm glad that I had it, but it definitely sort of gave me perspective on things and it made me realize a lot of myself and the type of person that I am and the type of person that my husband is.

Other participants echo the larger perspective, saying it allowed them to take a step back and become more patient and less reactive to others and comparatively minor events.

Some participants describe ambivalence in how much a part of their identity they want cancer to be. One participant says, "in many ways it has become my identity but in many ways it's not who I am because there's so much more to me than just the last year." Another describes wanting sometimes to "walk away" from the cancer world, and another says she doesn't want to be known as "the cancer girl". B., sarcoma survivor, says there are times where "I wish that I didn't think about it as much as I do. Or I wish that I didn't feel the need to bring it up, or think about it or talk about it. But...it happens." She also describes juggling her identity as a cancer survivor and being a graduate student:

I remember walking in on my first day and just thinking ‘wow, I’d be way more comfortable in an oncologist’s office than I am with these 160 healthy young adults’ because you start to think of yourself as a patient and you kind of stop thinking of yourself as just a normal person your age and so then when you’re expected to be a normal person your age, then you’re like wait, but that’s not my job, my health is my job!

Another participant described her relief at changing jobs after treatment so she could start over without cancer attached to her identity.

M., testicular cancer survivor, reports that people told him he was going to get perspective on his life, which “just didn’t happen”. He does discuss a shift for him in thinking about the availability of healthcare, and his access to top-tier care: “I wasn’t acknowledging my fortune as much as the injustice that there are other people that don’t have this.” Other participants discuss similar insights. One describes being glad that she works at an organization that raises awareness around a chronic disease, and jokes, “I’m changing the world!”

With identity and outlook shifts come some growing pains, and most participants responded that these changes had evolved – solidified, deepened, eased - as they got further out of treatment.

Evolution of Transition

Participants interviewed were in varied stages of their transition out of active treatment – from five months away from ending treatment to fifteen. Most (eleven out of twelve) identified that their experience of the transition had already changed and evolved as they moved further away from treatment and continued to integrate the shift in worldview and identity. All (twelve out of twelve) reported that they believed it would continue to evolve as they moved further away. While all the participants felt that cancer

would always be a part of who they are (discussed above), they imagined it would be to different degrees and different ways. Many identified the five-year mark, when the risk of recurrence for most cancers goes way down, a turning point, when they might not “obsess about it as much” and would see it as something they had been through that was not as “raw” or charged. A., Hodgkin’s survivor, who was eight months away from active treatment at the time of the interview, says:

I don’t think it will ever go away totally. I think there will always be a part of me that will – hearing about someone go through something worse, or somebody passing away – I think that’s always going to hit me hard. But at the same time, I would say at this point it’s very much at a manageable level where at the beginning I felt like it wasn’t manageable and it was much more all consuming all the time.

K., leukemia survivor, who was seven months out of treatment at the time of the interview, notes that evolution is almost inevitable because of the demands of non-cancer life:

I think it gets less 'cause you get away from it more because your new healthy life kind of comes in before your old one. But all it takes is seeing something, or one little – a memory of something to jog back to your experience. But I’m not – I’m not that far out of it yet, so I find it’s still raw for me.

D., Hodgkin’s survivor who was nineteen months out of treatment for his second recurrence, spoke of some resistance to the allowing in the demands of non-cancer life:

I kind of got in a mode for a while where I was comfortable just being as it was kind of...playing Peter Pan and just...being in the patient cancer mode where your parents take care of you and do everything for you and not have to really... trying to make that step to the next transition to being sort of more independent of yourself.

Like D., K., leukemia survivor, spoke of some things she would miss as her transition evolved:

I like to say now that life gets in the way of living my life. And that wasn’t like that when I was in the hospital and stuff – It was much calmer. As crazy as it

was, everything we were going through, it was like it was still calm. Because we only were focusing on one thing.

Like K., seven out of the 12 participants reported missing some aspect of the treatment process, and that adjustment to this was part of their transition. These seven talked about missing “the familial feel” in the treatment room, being the center of attention with their friends and family, having a “mandate to take it easy” and being around people who understood illness. None missed it enough to ever want to go through treatment again, but it is evident that noting that there are losses when treatment is over is important to understanding the trajectory of someone’s transition. In general, participants seemed able to take some comfort in the fact that they could see an evolution in the magnitude of their fears and the rawness of the experience and could infer that it would therefore continue to shift.

Some participants talked about the concept of being a survivor, and how that has evolved. M., breast cancer survivor, thought about the idea of a “JV survivor” or “survivor in training” before she felt she had gotten through the treatment and was in remission. She described getting to the point where “cancer was not ruling my life anymore” as a turning point in her evolution. N., breast cancer survivor, felt she considered herself a survivor from the moment of diagnosis, which allowed her in to a community of other survivors who were actively fighting the disease, in remission, or even cured.

Getting Involved

A notable theme in participants’ experiences, sometimes included in discussion of the evolution of their experience, was a desire to get involved in the cancer world. All

twelve were involved to some degree, as evidenced by their participation in this study. Ten described currently being involved in fundraising, awareness, or communities of survivors. Some were involved in all three. Five participants maintain a blog that they started during treatment; their intention is to share what they have learned with others who are going through the process. One participant who is not currently involved in an organization or community is in medical school studying to become an oncologist. The other used participation in this study as the first step to greater involvement. Participants were involved to varying degrees, and some acknowledged that they would like to become more so as they moved further away from treatment and their emotions became more tempered. N., sarcoma survivor, described this increased involvement, “I think I’ll think of [my cancer] less and I’ll want to help more, however I can, with other people going through it.”

Raising Funds and Awareness

Participants described either being a part of or spearheading fundraising efforts in their workplace or amongst their friends. Many had participated in organized walks to raise awareness and funds for research, such as the Race for the Cure or Light the Night. One participant started an agency-wide fundraiser for Daffodil Days, a fundraiser for brain tumor research. Another began a fundraising softball tournament with his family that he plans to continue on an annual basis. Half of the proceeds were given to a research foundation and the other half went to a young adult survivorship adventure

camp. Through these efforts, he was able to raise awareness in his community about his rare form of cancer.

Community

There are growing survivorship communities providing support and resources to survivors. Many of the participants are linked in with I'm Too Young for This, an organization focusing specifically on young adult survivors. J., a Hodgkin's survivor, reported the impetus for getting involved with this organization as wanting to provide support he did not have. He was part of support groups where he was the youngest by thirty years, and did not feel like he could relate to the others:

And then in April, I went to my first [I'm Too Young for This] event and it was there that I realized – I was in a room with hundreds of patients and survivors that were all in my age group and so I was really able to connect with my peers. And that's when I was like, this is really cool, this wasn't available to me when I was sick so how can I get on board and how can I help out or whatever. And that's what started my whole volunteering for [I'm Too Young for This].

Some research societies provide peer connection programs to link survivors done with treatment with those just starting. K., leukemia survivor, is not currently involved in any formal organizations, but has made herself available to others in her community who have been diagnosed with cancer. She recalls how helpful it was to her to speak with people who had gone through it, and notes she will continue to contribute more and more:

I feel like it's my new – it's what I want to do. Sometimes I'm like I don't want to – I didn't want to go back to work and doing what I did. I want to work and do something with this, with the information I've learned. I don't know what that is, but that's what I want to do. You know...in time.

A., Hodgkin's survivor, feels being involved in community will both serve others and move her along in the healing process:

At least with the experience I had, I can do as much as I can to help other people...I think the best thing to do to work though this is to get involved and to do something positive with it.

J., Hodgkin's survivor, underscores the importance of community and connection. She remembers when she first found a gathering of other young adult survivors:

It's great to have that connection with people. It's like if you meet someone that's had cancer, it's like an instant connection, you have something really big in common. I didn't quite realize how important community was until I actually started going, and meeting these people.

Those participants who maintain blogs also describe a mutually beneficial result.

D., Hodgkin's survivor, says his blog "started as kind of a way to express myself and evolved in a networking site too, an information site as well". N., sarcoma survivor, echoes these sentiments:

The blog was awesome. I used it kind of like a journal, so I could release whatever was going on and everyone could read without calling me. I think my best views of the month, I got like 20,000 views in a month. It was a place where people who also have that type of cancer could look and just see what worked for me...I hope it can show them what to expect and what they can do to have a better treatment.

In perusing these blogs, it is indeed a mixture of information about each person's own journey, links to others who have gone through similar journeys, and information sharing about cancer, survivorship, and community.

Participants uniformly spoke of the importance of involvement in the cancer survivorship community, whether or not they were current linked in. For most, being a part of a community and/or helping to raise money and awareness seemed to be helping them through the transition or be the next step in their experience. Many linked the importance of this with the uniqueness of being a young adult going through cancer.

Young Adults' Unique Experience

All the experiences described by the participants are tinged with evidence of their status as young adults. Many are single (seven out of twelve), one in a long-term relationship; several newly married (four out of twelve). One participant has young children; others are contemplating starting a family in the coming years. There was discussion of cancer delaying college or graduate school or creating difficulty as participants began new careers. All participants (twelve out of twelve) noted that their situation as a young adult having just finished cancer treatment was different than a child's or, like the majority of people they were in treatment rooms with, the middle-aged or elderly.

Dating & Fertility

Dating came up as something unique to young adults who had gone through treatment for cancer for five participants. Two participants mentioned a feeling of being “damaged goods” and a reluctance to share their recent history with potential partners.

M., breast cancer survivor, wonders:

How and when do you tell someone you had cancer? Because for me, it is something that's in my past. But I know a lot of people are scared by that...sort of when do you drop that bombshell and how and all of that associated baggage.

D., Hodgkin's survivor, expresses some “feelings of inadequacy” and frustration at the impact disclosing his cancer history might have on others: “I know that I'm a lot more than just my cancer and that cancer is just one element of a richer mosaic, but it's there and at some point that will come up”. Others struggle with this same question: How big a part of your identity do you want cancer to be in meeting potential romantic partners? N.,

breast cancer survivor, talks about the pros and cons of dating within the survivorship community – having someone who understood what you had gone through would be positive, but that she might miss the option to “avoid cancer in certain situations, just kind of walk away and say this is not my life. I feel like with a relationship, it would be great, but it would also be hard to always be thinking about it.” Closely linked in a discussion of dating was fertility, which came up frequently in a discussion of sequelae unique to young adults.

Nine participants out of twelve brought up fertility as something that was an issue for them before, during, and after cancer treatment. For the participants who want to have children in the not-too-distant future, especially those you went through chemotherapy, worry about whether or not they will be physically able to looms large. It is generally an unanswerable question, as “it’s one of those things I won’t know until I get there whether or not I can”, and contributes to a feeling of potentially being tainted or “damaged”. J., Hodgkin’s survivor, who had strong chemotherapy through a stem-cell transplant, says, of the fertility issue:

When I think about that, the whole cancer thing makes me mad, because it’s like I already had to deal with having cancer and chemo and the transplant and this and that when I was 25 and 26 years old, and now it’s like I had to deal with that and because of that I have this problem. It just doesn’t seem fair.

In addition to the question of whether or not they would be physiologically able to reproduce, several participants wondered, even if they were able, how long they should wait post-treatment in order to ensure they would not relapse. The ages of young adulthood are typically when people are partnering and starting families, and cancer

interrupts this process. Participants also spoke of the difficulty of worrying about their mortality when others were planning their wedding, and other differences that created distance between them and their peers.

Different than Peers/Lack of Mirroring

N., breast cancer survivor, described this distance she feels from friends:

A lot of my friends are having kids and getting married, and I think ‘I’m really happy for you and that’s great that you’re doing that’, but I can’t right now and that’s a hard gap to bridge. I think that dynamic has been strange sometimes.

Other participants described similar incongruencies with what their peers were dealing with. For some, it was a feeling of being left behind, and being forced back into childhood. One participant who had recently graduated from college before her diagnosis recalls that it felt “like everyone has new jobs and they’re getting apartments and new lives, and it was like oh no wait, you have cancer! It was like all of the independence you thought you were getting is now totally gone”. Another reported, “It makes me feel like I’m a child almost, and so that’s difficult to kind of go back to that.”

For those participants who were involved in some kind of young adult survivorship community, they found relief in meeting others their age that were going through it. For those who did not, their age was highlighted when they were not mirrored in infusion centers, radiation waiting rooms, or support groups. Many participants described going to support groups where they were the youngest by 30 years and noted, “I felt like I couldn’t just be myself”. For those who experienced isolation in the cancer community as well as with their friends, there was a general feeling of “I don’t fit in”.

For others, dealing with cancer felt like it came too early, and brought up things that they did not imagine having to consider at such a young age. One participant said, “I guess I felt like I wasn’t old enough to have to deal with these problems”. Several participants pointed out that they were done with cancer treatment, but in their transition to full-time survivorship, their status as a young adult with the potential of many years of life ahead of them was highlighted. K., leukemia survivor, says:

So I think that you’re left with all of these things, and like financial bills and medical bills, all of these things you’re left with now. You’re healthy, you have your life, but you have a lot of other things that are going to be around for a long time. But, you get your life.

Other participants felt this keenly, as they discussed their worries about insurance and finances in the future, as well as the possibility of long-term side effects of their treatment. Many felt that this was an understudied area, as most of the research was done on older adults.

One participant stated that as a young adult, “the medical community doesn’t know what to do with you”, and another feels that “awareness is not at the level that it should be. Several people mentioned that statistics show that this is the only age group whose survival statistics have not improved in several decades, and noted that this was because of a lack of research. Some of the participants, especially those who were involved in young adult survivorship communities or advocacy organizations, did not see the young adult status as a negative.

Increased Access to Media

For many of the participants who found relief in community, this community was largely based online. One of the participants, who is a public figure in one of the advocacy and community-building organizations, described having over 2,500 Facebook friends, most of whom were part of the survivorship community. He feels that young adults have an advantage in being able to create community and spread awareness:

Primarily it's just the access that we have to media to spread the word and advocate for others. Like someone who's in their 50's and 60's necessarily doesn't tend to be on Facebook or MySpace and Twitter and going on message boards and blogging whereas our generation: that's pretty much all we do.

A., Hodgkin's survivor, described the lack of awareness being the reason she is linked in: "I'm so happy to be getting involved with things like I'm Too Young for This, to kind of hopefully...change that. To feel like I'm doing something to proactively change that."

All participants keenly felt their young adulthood, whether this was a positive or negative thing. It was underlying the discussion of the other themes: Why some of the consequences of treatment were unexpected, reasons to get involved, and how to integrate their identities as a vibrant young adult with a new identity and worldview related to being a cancer survivor. It is a unique age to be when going through the transition from active treatment to full-time survivorship.

In the next chapter, I will review findings and include a discussion of the themes that arose, as well as identifying limitations to this research and directions to follow for continued exploration.

CHAPTER V

DISCUSSION

The purpose of this study is to examine the subjective experience of young adults as they transition from active cancer treatment to full-time survivorship. Available literature was reviewed on the subject of cancer survivorship, of young adults, and on the transition from the treatment phase to non-treatment. Questions were developed from this literature to further explore the unique position of young adults navigating this transition. Subjects ranged from a comparison of relationships during the different phases and positive or negative changes, to aspects that were surprising, either disturbingly or pleasantly so.

Major findings included themes of unanticipated consequences (aspects of the transition that did not meet the survivor's expectations or the expectations of the survivor's support network, fear of recurrence staying constant or increasing after treatment and feelings of helplessness at no longer doing anything to actively prevent relapse), a shift in worldview and or identity precipitated by the cancer experience and crystallizing post-treatment, and a desire to get involved or stay involved with the cancer world. Additionally, all participants described an evolution of their transition: that it had shifted since right after treatment ended and continued to change and take on new shapes. Lastly, all participants recognized their unique positions as young adults in the cancer community – some seeing it as a source of isolation and others as an opportunity, while some viewed it as both.

Many of these findings are supported by the literature. Little et al's 2002 article, from which the title of this study was taken, describes the quandary that the survivor finds oneself in, as they have no blueprint or manual from which to take direction. This "life lived in a context of new knowledge" (p. 176) is further muddied when one's expectations of how the experience should be do not match with the lived experience. Many of the survivor participants described this surprise and confusion based on their own expectations. The most common sentiment was an upset of the pre-existing notion that after treatment ended the cancer experience was over. This was sometimes distressing as the emotions that came up after treatment were stronger and more troubling than what they had dealt with from diagnosis through the cancer therapy, and appeared at a time when they were not prepared. Further, this often did not fit with the survivors' loved ones' expectations. One survivor shared the difficulty created as her mom does not understand why cancer still occupies so much of her thinking: "At the beginning, I felt relatively okay just getting through things on auto-pilot, then afterwards it was like she moved on and wanted me to do the same thing". This follows with Arnold's 1999 study which described the ending of treatment as a crisis, in part because there was a discrepancy between supporters' desire for a return to the pre-cancer self and the survivor's experience.

A major theme influencing the survivors' ongoing reactions, and endorsed by all but one of the participants, was a fear of recurrence of their cancer. One of the seminal studies on survivorship, Koocher's *The Damocles Syndrome*, describes this phenomenon eloquently. He uses the analogy, taken from an ancient Greek fable, of a bountiful feast laid out before someone who realizes, as they are marveling at the abundant

opportunities, that there is a sword hanging point down directly above their head, suspended by a single horsehair. Participants described awareness of this sword as well as of the feast, and the effects this had on their life, both positive and negative. Half the participants felt that this fear of recurrence, or the sword's blade, had increased since treatment ended. Arnold's 1999 study reports that the uncertainty is heightened by survivors' perception that they no longer have an active role in preventing the cancer from returning. Findings from this study are consistent with Arnold's in that respect, as many participants described an unnerving dissipation in the focus they had throughout treatment, resulting in feelings of lack of control and helplessness.

Young adults are at a unique place in their life to navigate such a transition, and perhaps feel the helplessness more acutely as they are used to taking an active role in their life. All participants were in the midst of at least one active pursuit at the time of diagnosis: College or graduate school, burgeoning careers, parenthood, relationships, relocation, and many were involved in multiple. Their cancer diagnosis interrupted this, but the illness also provided a point at which to direct their energies. With transitioning out of treatment, that point disappeared, and survivors were left to pick up where they left off or choose a new direction, with the added burden of a cancer history. The Adolescent and Young Adult Progress Report Group (AYA PRG) found that young adults had unique concerns in this transition, such as feeling different from their peers, worries about insurance and finances, and a wide range of sometimes conflicting emotions. Participants in this study widely reported feeling separate from their peers in outlook on life as well as because of their additional health concerns. Some described deeper and more nuanced view of the world than their friends, resulting in frustration or feelings of

isolation. All but one participant who already had three children reported questions about fertility, which concerned some to a greater degree than others. Most described a frustration with the lack of information they received on this subject, recounting their understanding that this was secondary to the oncologist's task of saving their life.

Participants ranged in the amount of time they had spent out of treatment, from five months to seventeen months. As mentioned previously, all described an evolution of their experience from directly after finishing treatment to the time of the interview. All believed that it would continue to evolve, and most postulated this would mean decreased worries about the uncertainty and increased integration of the experience. This is true of Cella et. al.'s study which reports that the time of greatest "psychological distress and psychosocial disruption" was within the first two years off of treatment (all participants in my sample) and lessened with time (1986, p. 616). There was also a correlation between amount of time in treatment (some were in active treatment for as little as three months) and reported difficulty adjusting post treatment.

An implicit theme in the literature as well as in the findings of this study is the "both, and" phenomenon of the cancer experience. From the interviews, it is clear that cancer is both an experience that no one would want to repeat and an experience that most could not imagine not having had. It both narrowed opportunities and created new ones. It follows, then, that the ending of treatment and transition into full-time survivorship carries some ambivalence as well. The AYA PRG reported this "both, and" in their study finding that the newfound uncertainty about life post-treatment could be "a source of distress" as well as "a catalyst for person growth...development of confidence and resilience, and optimism" (Appendix B, p. 42). Similarly, in a study of breast cancer

patients, Allen, Savadatti & Levy (2008) found that the termination of treatment was both “a welcome milestone” as well as “a time of great hardship, uncertainty, and isolation” (p.6). The findings in this study offer similarly inclusive views of the ending of treatment. While all participants were relieved to not be enduring chemotherapy or radiation, or recovering from surgery, some participants described missing parts of treatment. Some missed the closeness they felt with their loved ones, others missed being the center of attention. Many missed the single-mindedness of the goal to eradicate cancer from their body, as well as the permission or “mandate” to spend so much time relaxing. Yet this all existed within a resounding “no”: They would never wish to still be in treatment.

The findings support the contention put forth in the literature that the transition from active treatment to full-time survivorship is not a seamless one without bumps. The fable of Damocles can be looked at negatively, with a focus on the specter of harm that lies close at hand. The other element of that fable, however, is a bountiful feast of opportunity. Each survivor interviewed had a unique perspective on both the uncertainty as well as the eyes through which they now viewed that feast. Their descriptions of their transitions were evidence of the importance of the transition and the varied ways of finding new equilibrium after the solidity of treatment is removed. Ward et al. (1992) describe active treatment as a “tentative equilibrium” within the cancer experience, and the ending of it disrupts this. Therefore, the task of this transition time is one of integration: What did my experience mean? What does it mean that the active treatment is over and I am alive? Can I go back to who I was before? Do I want to? What if I get sick again? Am I thinking about this too much? Most of these questions do not have

answers, as the participants reported, and so it becomes a matter of regaining one's footing on a shifting, unpredictable surface.

If conceptualized through a self-psychological perspective, we can imagine how each young adult participant's identity shifted as they were suddenly and unexpectedly seen by the external world as a sick person. With the next transition, the ending of treatment, others are easily able to view them as well again, but there is perhaps a lag in the survivor's own experience of themselves, as they have a formidable task of acknowledging major internal changes. Arnold's study reported this discrepancy, and it is borne out by respondents in this study. Little et al. (2002) describe a discontinuity of experience as characterizing cancer survivorship, and this can combine with a potential conflict between internal experience and external expectations to create disruption. In self-psychology, we learn that "empathic attunement is the necessary facilitator of development" (Berzoff, Flanagan & Hertz, 2002, p. 179). So while disruption is not harmful, and can, in fact, stimulate growth, if the survivor's experience is not being mirrored and is seen as aberrant, development will potentially be slowed. It is therefore the responsibility of the helping professions, in which social workers are well placed, to raise awareness of the potential for difficulty and facilitate normalization and space for growth to occur.

Strengths and Limitations

This study represented an exploratory, qualitative study into the experience of young adult survivors as they transition out of active treatment. A question guide was created at the outset that evolved as the interviews progressed. With this guide, the researcher was able to get at the many aspects of the question posed, and because of the

flexibility of the method chosen, questions could be modified as needed. A qualitative study was chosen in order to include the nuances and variability of each person's experience. As a result, there were overarching themes, with an understanding that each person's experience was unique within those broad categories. Within the criteria set, there was a range of participants with regards to age, gender, cancer diagnosis, and treatment received. Therefore, it is the contention of this researcher that the findings are both valid and reliable and can be generalized to a subset of the young adult survivor population.

One major limitation is the self-selection piece in the interviewed participants. Because of the limited time frame of the study, the study was conducted with a convenience sample of people who saw the interview request either on a young adult survivor blog, through a cancer support center, or who were part of a network to which the request was circulated from these sources. Because survivors are not necessarily linked in to oncologists and cancer centers, as the medical portion of their treatment is over, participants were already narrowed by who continued to remain in touch with the cancer community. Therefore, this limits the range of responses. Perhaps those who did not respond to this study request would represent a group who feel that their cancer experience ended when the medical treatment terminated. More research is needed to determine if this is the case.

Racial and ethnic diversity is also another major limitation. Of twelve participants, only one was African-American, and the rest identified as Caucasian. While it is tempting to speculate about the specific reasons for this, this author would put this forth as another area for continued research while noting that my own identity as a

Caucasian woman might have had some effect. It also raises questions about the current health care environment. The AYA PRG report notes an inequity in access to cancer treatment and the role of race, ethnicity, and socioeconomic status in the reaction to cancer and other health problems. Because of its lack of diversity on these fronts, this study does not provide answers on that subject, but does raise more questions.

Implications for Social Work Practice

The social work field in general is complicit with the expectation that the cancer experience ends on the last day of treatment, as evidenced by the lack of formal support programs through cancer centers. However, this study confirms that this ending is an artificial one. One participant, A., shares that she was a “model patient” during treatment:

And then when treatment was over, I just kind of got lost all of a sudden. And I really felt like nobody understood that at all. Like that’s when I started to freak out, that’s when I started to break down...And you know, when treatment is over...everybody else sees that as the end point. They’re like “oh, this is great” and they send flowers and presents and just are so happy this is over. And I didn’t feel like it was over at all.

It is our job as social workers to begin to understand the cancer experience as a process, and provide interventions that speak to this. Whether providing therapy in private practice or as advocates in a hospital, there is an opportunity for social workers to offer continuity in a potentially disruptive and discontinuous time. Social workers can help to normalize the experience, and allow space for young adult survivors to sit with uncertainty, integrate new knowledge, and take next steps. The literature offers suggestions that putting interventions in place to provide support through this transition is an essential aspect of cancer treatment (Allen et. al, 2008; Hewitt, Greenfield & Stovall,

2006) and that social workers are the natural professionals to do so (Black, 1989). This study further confirms this need.

It is my recommendation that social work departments within hospitals begin to develop such a program as part of the medical treatment for cancer, and that social workers within other agencies collaborate with medical centers or cancer support centers to create a continuous web that is available to people as they finish treatment. These programs should be young adult-specific to address their unique needs, and flexible to allow for input from participants. My belief is that this should be offered to every young adult who receives treatment for cancer even if a patient does not explicitly request support. In this way, there is an acknowledgement simply in the offering of the importance of the transitional time, as each survivor finds her own way to mingle the pieces of her previous life with her cancer patient life and rearrange them into a container of a different shape to accommodate the newfound knowledge.

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Appendix A
APPROVAL LETTER

November 20, 2008

Zpora Perry

Dear Zpora,

Your amended materials have been reviewed. You have done an excellent job with your revisions and your additions and all is now in order. We are happy to give final approval to this most interesting study. Your open ended questions are excellent and I am sure will bring forth your participants' stories. The word "journey" was well chosen.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project

Good luck with your project.

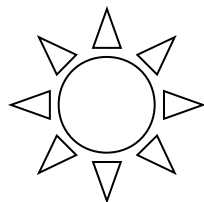
Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Cara Segal, Research Advisor

- Are you between the ages of 18-35?
- Are you within two years of having finished treatment for cancer?

Tell Your Story



I am a graduate student in social work, and a cancer survivor. I am writing my thesis on young adults' experience transitioning from active treatment to survivorship.

If you are interested in telling your story, please contact me by e-mail or phone (contact info below).

I look forward to hearing from you.

Appendix C

INFORMED CONSENT

November 2008

Dear Potential Research Participant:

My name is Zpora Perry, and I am a graduate student at Smith College School for Social Work in Northampton, Massachusetts conducting a study for my Master's thesis. I am doing research on young adults transitioning out of active treatment for cancer into full time survivorship. I want to find out about your experience as you go through this process because I think it is an important time and one that is not often talked about. Your perspective is vital to beginning to understand what is helpful and what is difficult and where health care professionals as well as friends and family can ease the process.

You are being asked to participate because of your unique position as a young adult on this phase of the cancer journey. I am interviewing people between the ages of 18-35 who are within 24 months of having finished active treatment for cancer. I am not planning to interview people whose illness is terminal. If you choose to participate you will be asked to answer a brief demographic questionnaire and return it to me, as well as participate in an approximately hour long interview that will be audio-recorded. In the demographic questionnaire you will be asked some general information about yourself. In the interview itself, I will ask you to share your thoughts and reflections about your experience of this transition. During the interview, I hope you will feel free to elaborate on any of the questions and/or insert any additional comments you may have on the subject at the end of the interview.

All identifying information on the demographic questionnaires or in my records will be removed from the data. In this way, I can ensure that confidentiality will be kept when transcribing and recording the data from the interviews. I will be the only handler with the collection of data including transcripts. My research advisor will have access to the raw data only after all identifiable information is removed. In reporting the data, I will not use names and will disguise vignettes. I will only report demographic data as a whole. I will keep the transcripts and questionnaires in a locked storage area for three years, consistent with federal regulations. Should I need the data beyond this period, I will continue to keep it in a secure location. After the three-year period has expired or after the data are no longer needed, all material will be destroyed. As stated above, the data will be used for my thesis, and may be used for future presentations and publications.

There will be no financial benefit for participating in this study. However, participation will allow you to share your experience as someone going through a part of the cancer process. Your contributions will provide important information that may be utilized by health care professionals working with people dealing with cancer as well as caregivers

and friends and family members. It will also provide vital support to other young adults who are seeking encouragement and community as they transition out of being a cancer patient.

There are some potential risks of participating in this study. During the interview, I will ask you about your time in active treatment as compared with your life now. I will ask you to reflect on significant events, both positive and negative, and on how cancer has shaped your identity. This could potentially bring up intense and painful feelings as you could access some difficult memories. I hope you will all make use of your friends and family as things come up as well as any counselors and therapists you are already linked in with. I have also included a list of referral resources for local cancer support centers and psychotherapy clinics if you want further support in dealing with things that might come up for you over the course of the interview.

Participation in this study is voluntary. You can choose not to answer any question during the interview without penalty. You have the right to withdraw from the study at any time: before, during, or after the completion of the interview, until March 30, 2009, when the report will be written. If you choose to withdraw, I will immediately destroy all materials pertaining to you. Please feel free to contact me (information below) if you have any questions. You can also contact the Chair of the Smith College School for Social Work Human Subject Review Committee at (413) 585-7974 with any concerns.

YOUR SIGNATURE BELOW INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION; THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION AND YOUR RIGHTS; AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

I thank you for your time, attention, and willingness to consider participation in the study.

Signature of Participant

Date

Signature of Researcher

Date

If you have any questions, or wish to withdraw from the study, please contact:

Zpora Perry

Please keep a copy of this for your records.

Appendix D

REFERRAL RESOURCES

National Resources:

CancerCare

<http://www.cancercares.org>

(800) 813-HOPE

Provides free, professional support services for anyone affected by cancer, including counseling (in-person or over the phone) and support groups.

I'm Too Young for This

<http://www.i2y.com>

(877) 735-4673

Online community for young adult cancer survivors (anyone from diagnosis forward), providing support, advocacy and education. Numerous links to informational and supportive resources and local chapters.

Lance Armstrong Foundation

<http://www.livestrong.org/cancersupport>

(866) 467-7205

Provides counseling and referral services by telephone and online.

National Mental Health Association

(800) 273-8255

(800) 969-6642

Provides free information on specific disorders, referral directory to mental health providers, national directory of local mental health associations.

Ulman Cancer Fund

(888) 393-3863

<http://www.ulmanfund.org>

Provides services specifically to young adults, including peer support and information exchange by telephone.

Appendix E

INTERVIEW GUIDE

1. Tell me a little about your cancer journey...
2. Tell me about your support system that you have had throughout this journey...
3. What are the main emotions that come up for you when you start thinking/talking about your cancer?
4. Do you think about recurrence more or less now than you did when you were in active treatment? Why do you think this is?
5. What is different about your amount of contact with your oncologist and oncology nurses? What are the effects on you of this difference?
6. Is there a difference in your relationships with your family and friends? If so, what are the positive changes and what are the other changes?
7. What are ways in which cancer has affected your identity? Does it feel like a major part of it?
8. What are some ways cancer has affected your outlook on life or your worldview?
9. If you consider yourself a survivor, at what point did you start thinking of yourself that way?
10. What do you see as unique about your situation as a young adult dealing with cancer?
11. Is this how you imagined the transition out of active treatment?
12. How do you imagine your thinking about cancer will change in the next three years? In the next six?
13. When you think back to the day that you finished treatment, can you remember any predominant emotion? Do you remember a predominant emotion from your family and friends?
14. Having had your experience, is there advice you would give to people who are nearing the end of their active treatment and moving toward full time survivorship?

15. Do you ever miss being in treatment?

16. What formal survivorship services do you utilize? If you don't, would you like to, and what would they look like?