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SOCIAL MEDIA INTERACTION AND SELF-PERCEPTION IN ADOLESCENTS AND
YOUNG ADULTS WITH CANCER

By

Sarah Daniels

A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

Major: Educational Psychology and Research

University of Memphis

December 2021

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Dedication

To every adolescent and young adult facing cancer, you deserve to share your stories, to feel supported, and to receive exceptional care. Even in life's most difficult moments, remember that your voice is important. This manuscript is dedicated to you.

Acknowledgements

Reflecting back on my time as a doctoral student, it is impossible to imagine arriving at this point without the generous and endless support of my family, friends, and academic and professional mentors. I would first like to thank my partner, Will Gietema, for his steady support of my dreams. You encouraged me throughout this program and made me believe it was possible to continue despite any unexpected challenges. You listened to me ramble on, sometimes for hours, about my coursework, my ideas, and my obstacles. Your patience and belief in my ability to succeed motivated my drive. Celebrating this accomplishment with you by my side is the ultimate reward that I will cherish forever.

To my family: Doug, thank you for teaching me to step outside my comfort zone, for keeping me competitive, and for being my number 1; Dad, thank you for passing down incredible writing and editing skills and for always cheering me on; Drs. Mom and Moody, thank you for setting the example of being life-long learners. To all of my friends, who continued to invite me places knowing I would have to decline (or knowing I would at least bring my laptop), thank you for accepting me and throughout this journey. Your friendships reminded me how to balance, making sure these past few years would provide memories beyond my doctoral work.

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Abstract

Daniels, Sarah. PhD. The University of Memphis. December 2021. Title. Major Professor: Denise Winsor, PhD.

The unique psychosocial needs of adolescents and young adults (AYA) with cancer are often overlooked or left unmet during treatment (Zebrack, 2011). Self-development is an important task for all AYA, and it is often informed by social interaction (Goffman, 1959). Given that social interaction among AYA occurs in offline and online spaces, the role of social interaction on social media for self-development is curious (Calvin, 2020). But examining this relationship also requires thoughtful attention by researchers to adequately describe the population being studied (Davis et al., 2020). As such, this exploratory sequential mixed methods research study sought to address the following research questions: (1) How do AYA with cancer describe their social interactions on social media since diagnosis? (2) What social and illness factors are most important for self-perception in AYA treated for cancer? and (3) How do stories from AYA with cancer about social interactions on social media inform our understanding of self-perceptions in many AYA treated for cancer?

Through semi-structured photo-elicited interviews with 8 AYA with cancer, ages 15-21, patients described social interaction on social media through four themes: (1) enacting active and passive engagement depending on the platform, (2) changing habits due to aspects of treatment, (3) evaluating and protecting self-image, privacy, and time (4) accessing and interpreting the meaning of social support. A building phase of the study revealed that the relevant social and illness variables to consider for this population were changes in engagement habits, both in frequency and in platform preferences, the practical and psychological impacts of cancer, and the complicated roles of social support from off- and online networks. Quantitative exploration of these factors in addition to self-perception scores in a sample of 12 AYA treated for cancer, ages

15-22, reinforced, expanded, and differed from the qualitative findings, demonstrating the importance for future research to examine the relationships between these concepts. Through a process of building side-by-side joint display tables, a mixed method integrative analysis demonstrated that it is important to (1) examine social media engagement habits when studying self-perception in AYA with cancer (2) recognize the individuality among AYA with cancer in the role of social media interaction and in self-perception outcomes and (3) acknowledge the complicated roles of social and illness factors for AYA with cancer. Taken together, the findings from this study importantly demonstrate the need for more research evaluating the relationship between social interaction on social media and self-perception in AYA treated for cancer. Additionally, these findings show the importance for health care providers to incorporate assessment questions about social interaction online when working with psychosocial aspects of AYA cancer care.

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CHAPTER 1

When I first thought about becoming a child life specialist, I pictured myself using play, creativity, education, and communication to compassionately support children and their families in hospital settings. I understood that the hospital could be a scary place, not only for sick children, but for the entire family as well. In my first two years working as a child life specialist, I assessed the needs of patients ages 0-10 years with leukemia and lymphoma and provided interventions to support their coping and adjustment to diagnosis and treatment. I used the language of children to provide these interventions: play. My toolbox included play-doh, storybooks, stickers, crayons, dolls, light spinners, and countless other toys that I adapted the use of to provide education and support in times of stress. My academic and clinical internship experiences prepared me well for this role.

When our child life program adjusted to a new staffing model, I was asked to move into a role working as a child life specialist for adolescents and young adults (AYA) with brain tumors. I agreed, knowing that I would be challenged to develop a new toolbox and a new understanding of how to use play to meet the needs of our oldest patients. One of my first consults was from a physician who introduced me to a 22-year-old male who had been initially diagnosed with a brain tumor at age 14 and had a poor prognosis. He had high generalized anxiety and had already experienced every type of procedure and treatment we had to offer. He had a good understanding of his diagnosis and was unwilling (and unable) to engage in social activities in the teen room, which has an upper-age limit of 19 years. My typical child life interventions to provide preparation, education and social support through play were challenged. I didn't know what I would provide for him, but I knew I didn't want to be a provider who ignored the lack of appropriate space and intervention for someone his age to make meaning of his life and legacy.

During the five months from our initial introduction until his death, I learned more about myself, the child life profession, and the impact of cancer on AYA life than I ever expected. I built rapport and trust through conversations about TV shows and social media and learned that his favorite pastimes were watching Gilmore Girls with his older sister and creating playlists with friends online. I learned that he worked part time at a video game store and took classes at a local university; he was an uncle, had a dog, played guitar, and recently started dating. But as I listened to him share his life experiences, I also heard him confront his own mortality, grieving milestones that he would never reach. He felt a gradual loss of physical and social independence, feared that he would never fulfill his academic and vocational goals, struggled with romantic insecurities, and expressed a disrupted sense of self.

Throughout our time together, I learned that conversation, listening, and social connection were some of the strongest tools in my child life specialist toolbox. I discovered that 'play' in the hospital for an AYA sometimes looks like video gaming or crafting, but it more often looks like maintaining social connection (often through social media) and exploring the meaning of diagnosis and identity. Our interactions provided spaces for this patient to reconcile his illness experiences with his sense of self and to express how he wanted to be remembered. Our interactions also provided spaces for me to witness the unique challenges faced by AYA and to dream about ways to better support them through those hardships. When I think about being a child life specialist now, I still picture myself using play to connect with patients of all ages, but I have become especially passionate about understanding the meaning of play in AYA social experiences and using this understanding to advocate for their needs as they remain largely unmet in pediatric settings.

Introduction

Each year, 70,000 adolescents and young adults (AYA) aged 15 to 39 years receive a cancer diagnosis (National Comprehensive Cancer Network [NCCN], 2019). This number is seven times the amount of pediatric cancer cases diagnosed each year (Siegel et al., 2018). Despite the high number of AYA cancer cases compared to pediatric ones, AYA with cancer have less access to clinical trials, poorer survivorship outcomes, and experience disruptions to psychosocial development in ways that are very distinct from the stressors of pediatric patients (Zebrack, 2011). When AYA seek treatment for cancer, there is no clear designation as to whether they should receive treatment directed by a pediatric or an adult oncologist. This ‘gray area’ is especially vague among AYA in their late teens and twenties (Fort Worth AYA Oncology Coalition [FWAYAC], n.d.). At times, AYA in their teens and twenties have better outcomes when treated by pediatric oncologists, but two-thirds of AYAs are not seen by pediatric oncologists (FWAYAC, n.d.). AYA treated in adult facilities may find fewer resources that directly support their developmental needs, but this is also true for AYA treated in pediatric facilities. Although children’s hospitals have more programming and activities to support AYA coping and development, AYA still report feeling like they are “baby-ed” and do not fully fit in (Barakat et al., 2016).

At time of diagnosis, some AYA have already started college, become a parent themselves, and are living independently. AYA are at higher risk of divorce, experience significant psychological morbidities (including anxiety, depression, and traumatic stress), have impaired vocational functioning, and experience social isolation extending into survivorship (Kirchhoff et al., 2012; Muffly et al., 2016; Vetsch et al., 2018). Understandably, while cure is the top priority for AYA, they report several other high priorities for their care including

returning to school/work, maintaining relationships with friends, and normalizing their circumstances (Graetz et al., 2019).

Today, there is only one institution in the United States that is staffed, designed, and programmed by medical and psychosocial providers who specialize in AYA oncology (FWAYAC, n.d.). But there are several other institutions that have distinct AYA oncology programs within pediatric and adult facilities. These programs strive to provide excellent, developmentally appropriate care to AYA patients by promoting independence, education, and support. When asked about what AYA would prefer to receive from an AYA oncology program, their primary requests are for support with reintegration into sports, school, and friendships, for dealing with physical changes and improving body image, for educating their family and friends about their experience, and for overall coping with cancer and treatment (Barakat et al., 2016). It is not surprising that these requests directly correspond with the biggest challenges that AYA report: missing friends, not being able to work, lack of physical activity, feeling different than peers, and being in the hospital/undergoing medical procedures (Barakat et al., 2016).

It is important that AYA oncology programs help AYA continue development in a healthy way. One indication of healthy psychosocial development is high self-perception. Self-perception is the way one evaluates the self and is comprised of several factors including global self-worth/esteem, scholastic competence, social competence, athletic competence, physical appearance, job competence, romantic appeal, behavioral conduct, and close friendship (Harter, 2012b). It is a common assumption that youth impacted by serious medical conditions or disabilities will have lower self-perception than healthy youth due to the stressors they face (Harter, 2012b). Consider some of the unique circumstances for an AYA with cancer: they experience side effects from treatment that make them feel physically weak and that alter their

physical appearance, they endure frequent hospitalizations that disrupt their school/work and social routines, and they have limited opportunities to exercise independence (Zebrack, 2011). These circumstances undoubtedly relate to several aspects of self-perception, such as athletic competence, physical appearance, friendship closeness and social competence. However, Harter (2012b) was unable to confirm a difference between healthy and medically affected youth in a thorough literature review containing a decade of research. Instead, data indicated that medically affected youth did not differ from healthy youth and had relatively high reported self-perceptions related to self-esteem and appearance (Harter, 2012b).

Harter (2012b) offers a few possibilities for the lack of difference in self-perception among youth with medical conditions and healthy youth. One possibility is that youth with medical conditions compare themselves to others like them (Harter, 2012b). For instance, when evaluating features such as appearance, youth with cancer may compare themselves to other youth with cancer rather than to healthy youth. This strategy would indicate that youth with cancer are able to alter their expectations of themselves given their medical circumstance. Another possibility is that youth are responding to measures in a favorable way in order to cope or to reconcile their real and ideal selves (Harter, 2012b). These are just a few possibilities that demonstrate some considerations to make when evaluating and interpreting self-perception in youth with medical conditions.

Although Harter's (2012b) review was comprehensive at the time, her assertions were supported with research published from 1999 to 2008, before the dramatic rise in social media use among AYA. Instagram, one of the most popular social media platforms used by AYA, launched in 2007; this means many AYA today have never experienced life without social media. In fact, among AYA in the United States, 88% to 97% report using at least one major

social media platform (Pew Research Center, 2018a). An updated understanding of self-perception thus requires consideration of the role of social media, both for healthy AYA and for AYA with medical conditions.

The unique affordances of social media as a platform for self-presentation and peer interaction play a role in self-development (DeVito et al., 2017; Uhls et al., 2017). While social media may serve as a convenient space to access social support, AYA with physically apparent medical issues are known to hesitate from using social media if they perceive potential to receive negative peer feedback (Holmberg et al., 2018; Vaala et al., 2018). However, AYA with cancer crave normalcy and engaging in social media interaction with peers is a normal activity that can be maintained throughout treatment. Some research is beginning to explore the role of social media as a source for social support, health information, and digital intervention for AYA, but the role of social media interactions on self-perception in AYA with cancer has not yet been directly studied (Aggarwal et al., 2020; Domínguez & Sapiña, 2016; Gentile et al., 2018; Walton et al., 2017).

Studying self-perception is complex in any population, but it is an especially intricate task to study self-perception in populations with unique developmental, medical, and psychosocial circumstances. Harter (2012b) urges researchers who wish to study self-perception in populations with medical conditions to begin with an appreciation for the complexities associated with self-perception in special populations. She says evaluations of self-perception in these populations should not rely on a single assessment procedure but should instead carefully consider the various dynamics contributing to self-perception (Harter, 2012b). It would be irresponsible to distribute questionnaires assessing social media interactions, illness variables, and self-perception in AYA without first exploring the existing dynamics of those contexts

today. Therefore, this study uses a qualitatively driven mixed methods research approach to frame the study of social media interactions and self-perception in AYA with cancer from the perspective of AYA themselves.

Statement of the Problem

The problem addressed in this study is that AYA with cancer experience several disruptions to their psychosocial development and while their interactions on social media may help mitigate some common stressors, they may also play a harmful role in their development of self-perception throughout treatment. Self-perception is importantly related to well-being; fostering positive self-perception throughout treatment may help AYA continue development in a healthy way. As AYA face the unique and significant challenges of cancer treatment, high self-perception may reduce distress and promote coping into survivorship.

Studying the role of social media in healthy AYA development is common and findings demonstrate that interactions with peers on social media relate to self-esteem, friendship quality, and sense of self (Borca et al., 2015; boyd, 2014; Chua & Chang, 2016; de Vries et al., 2016; Shapiro & Margolin, 2014; Uhls et al., 2017). But this role is likely complicated for AYA diagnosed with cancer as they begin to use social media under new circumstances that include changing physical appearance, separation from peers, and a general disruption to normalcy. Some AYA with cancer use social media to share illness narratives, maintain normalcy, and seek health information (Maor & Mitchem, 2018; Myrick et al., 2015; Peat et al., 2019). While interacting in these ways on online patient communities is supportive for AYA coping and adjustment (i.e., Domínguez & Sapiña, 2017; Keim-Malpass et al., 2016; Perales et al., 2016), less is known about the role of social media interactions between AYA with cancer and their healthy friends (Chou & Moskowitz, 2016). AYA with cancer report different feelings toward

hospital peers and healthy friends (i.e., Kaluarachchi et al., 2020), but social support from friends remains an important aspect of AYA coping throughout treatment (Breuer et al., 2017). Further exploring AYA relationships with healthy friends in the context of cancer treatment and social media is important. If this problem is not addressed, healthcare providers may continue to support social media as a platform for meeting AYA needs of normalcy and social support without an understanding of the simultaneous impacts on self-perception. By further investigating the role of social media interactions on self-perception, healthcare providers can more confidently advocate for social experiences that support the coping and developmental needs of AYA throughout treatment and into survivorship.

Purpose of the Study

The purpose of this mixed methods study is to understand the social media interactions of AYA cancer patients since diagnosis and to determine how aspects of those interactions associate with AYA self-perception during treatment for cancer. An exploratory sequential design was used to explore variables related to social media interactions and self-perception among AYA cancer patients based on AYA perspectives. Data were collected as part of a larger study at an academic research hospital in the mid-south region of the United States. The first phase of the study is a qualitative exploration of AYA cancer patients' social media interactions. In this initial component, photo-elicited interview data were collected during semi-structured interviews from a sample of 8 cancer patients ages 15-22 years. The results of the qualitative data were used to contextualize the social and illness variables that are important for self-perception in AYA with cancer. The second phase of this study was built from the results found in the qualitative phase. This phase used quantitative descriptive assessment to observe the relevance of social and illness variables and self-perception in a larger sample of AYA with

cancer. Questionnaires were collected from a sample of 12 patients treated for cancer ages 15-22 years at an academic research hospital in the mid-south region of the United States.

Theoretical Framework

The theoretical framework for this study integrates a guiding macro-theory, a mid-level theory of development, and two micro-theories, one for each phase of the study. A visual representation of this framework is displayed below:

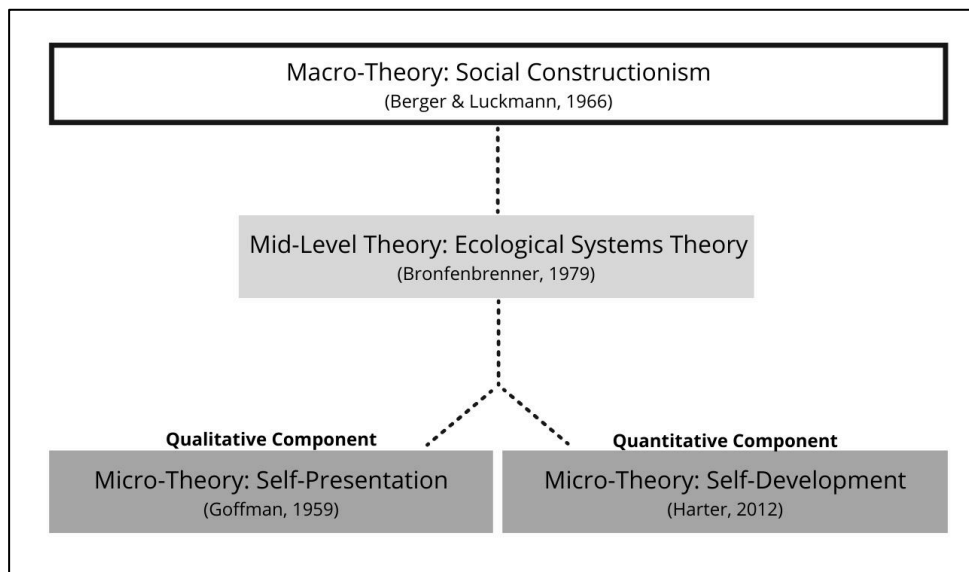


Figure 1. *Theoretical Framework*

The guiding macro-theory for this study is social constructionism. This theory is well known to social scientists as rejecting the modernist and structuralist views that there are underlying truths and structures of human psychology and sociology waiting to be discovered (Burr, 2015). Instead, reality is socially constructed through interpersonal interactions and knowledge is a part of the analysis of such interactions (Berger & Luckmann, 1966). To analyze reality, Berger and Luckmann (1966) emphasize the importance of not relying on observations alone. Instead, it is important to consider subjective realities that coexist and evaluate the

communication of shared meaning through exchanged language and symbols (Burr, 2015).

Social constructionists view the world in specific historical and cultural contexts and emphasize that knowledge and meaning are co-constructed through social interaction (Burr, 2015).

The developmental theory framing the interpretation of AYA development in this study is Bronfenbrenner's Ecological Systems Theory (1979). Bronfenbrenner (1979) said that in order to understand the developing individual, one cannot simply isolate the individual in a laboratory and observe their abilities and responses to interventions because several contextual factors will be unknown and ignored (Muuss, 1996). The core concept of Bronfenbrenner's (1979) theory is that development should be viewed as the product of interactions occurring between the person and the environment (Muuss, 1996). Importantly, the environment is not simply defined as the immediate setting within which the individual interacts. Rather, there is an emphasis to explore interpersonal structures, roles and social positions, cultural and political value systems, and other broad contexts for development (Bronfenbrenner, 1979).

These contexts are categorized within four types of ecological systems: the microsystem, the mesosystem, the exosystem, and the macrosystem (Muuss, 1996). Together, these ecological systems interact with one another and provide a nest for individual development (Muuss, 1996). The most central system to the developing individual is also the most widely studied among other developmental theorists: the microsystem (Bronfenbrenner, 1979). The microsystem consists of the physical environment and face-to-face social interactions in which the individual engages most frequently (Muuss, 1996). Individuals, especially adolescents, belong to several microsystems and the interplay of these systems is referred to as the mesosystem (Muuss, 1996). It is within the mesosystem where an adolescents' differentiated roles may be explored and

understood further (Muuss, 1996). The microsystems explored in this study are social media, peers, and the hospital.

The qualitative phase of this study is supported by Goffman's theory of self-presentation (1959). Goffman (1959) theorized that individuals are motivated to manage their presentations in different contexts. The management of self-presentation is also referred to as a process of impression management (Goffman, 1959). Social interaction is a key feature of impression management: individuals engage in self-disclosure and expression through behavior and language and then interpret others' feedback to these presentations (Goffman, 1959). Individuals then integrate their evaluations of the feedback into future representations of the self (Goffman, 1959). Social media is a newer platform for individuals to engage in self-presentation. In the qualitative phase of this study, the aim is to understand AYA experiences on social media since diagnosis, including their self-disclosure of cancer, their presentation of self through image and language, and their interpretation of peer feedback. Self-presentation theory informs the interpretation of these experiences by considering the role of these interactions on self-development.

The quantitative phase of this study is supported by Harter's theory of self-development (2012b). Harter is a leading researcher in the sociocultural and developmental foundations of self-development. Harter considers both cognitive and social constructions of the self and acknowledges the influences of different settings on individual self-development (Harter, 2012b). Her approach to understanding self-development allows her to differentiate several aspects of the self and confront the complex challenges of studying the self. Harter designed the self-perception profile for adolescents and young adults which assesses AYA self-evaluations across different contexts. In this study, Harter's (2012b) theory of self-development supports the

interpretation of illness variables related to social media interaction and self-perception in AYA with cancer.

The perspectives in this theoretical framework all largely consider the relevance of context and social interaction. Each acknowledge the importance of operationalizing context-specific variables rather than assuming universal truths. These theories work together to support the use of mixed methods in order to first contextualize self-presentation on social media for AYA with cancer and then to consider the implications of those interactions on self-perception among a larger group of AYA with cancer.

Research Questions

The following research questions guide this study:

- (1) Qualitative: How do AYA with cancer describe their social interactions on social media since diagnosis?
- (2) Quantitative: What are the relationships among social support, cancer impact, and coping on self-perception in AYA with cancer?
- (3) Mixed Methods: How do stories from AYA with cancer about social interactions on social media inform our understanding of self-perceptions in many AYA treated for cancer?

Significance of the Study

This study explores the relationship between social media interactions and self-perception in AYA with cancer. By asking AYA to share stories about their social interactions on social media since diagnosis, this study provided an opportunity for AYA to shape the perspectives that providers hold about their peer relationships and activities. Documenting this information is one way for providers to learn from AYA and enhance therapeutic relationships

with their patients. From these narratives, providers may ask their own patients about their experiences on social media and consider supportive interventions to foster healthy development related to those experiences. Additionally, the quantitative phase of the study highlights shared meaning of these perspectives in several AYA with cancer. By testing the associations of patient-reported variables in a larger population, there is a possibility to design interventions that meet the needs of several AYA. This information is also be useful for stakeholders building new AYA oncology programs.

CHAPTER 2

Literature Review

In Chapter 1, readers learned the purpose of this study is to examine the relationship between social media interactions and self-perception among adolescents and young adults (AYA) who are diagnosed with cancer. Although an introduction to the theoretical framework for this mixed methods study was briefly discussed, Chapter 2 provides a more detailed overview of this framework as well as introduce the conceptual framework for the study with a review of the literature related to these concepts. There are four key components for social research studies: epistemology, theoretical perspective, methodology, and methods (Crotty, 1998). It is common for researchers to discuss a concept while using language such as ‘research approach’ or ‘perspective’ interchangeably and without giving distinct organization to these items (Crotty, 1998). Importantly, each component of a social research study should inform the selection of the other, to compose one coherent research plan. Therefore, the sections of Chapter 2 are intended to describe the epistemological and theoretical justifications for the proposed conceptual framework. A review of the literature related to the conceptual framework follows. Elements from these sections later provide context for the methodological decisions proposed in Chapter 3.

Macro-Theory: Social Constructionism

In social research, macro-theories serve as an orientation toward the researcher’s assumptions about knowledge and reality and are often linked to the discipline of the researcher (Crotty, 1998). The macro-theory for this study is social constructionism, which stems from various disciplines in the social sciences, primarily sociology and psychology (Burr, 2015). Social constructionism is a movement which grew from several key thinkers, including French poststructuralist philosophers Michel Foucault and Jacques Derrida who contributed to the social

constructionist focus on language and discourse, sociologists Peter Berger and Thomas Luckman (1966) who contributed a book, *The Social Construction of Reality*, detailing the relevance of social processes and interactions in the study of humanity, and social psychologist Kenneth Gergen (1973) whose paper, 'Social psychology as history', supports the social constructionist view that knowledge is influenced by culture and history (Burr, 2015). In sum, social constructionism is, "the work of a cast variety of authors concerned with cultural, historical, socio-linguistic and context-dependent meaning-making processes" (Aceros, 2012, p. 1002).

The philosophical underpinnings of social constructionism date back to the Enlightenment period, but social constructionism began to formally emerge as an epistemological theory in the 1980s (Hung & Fung, 2020). Its emergence occurred largely in response to the positivist school of thought, which seeks to discover essential, objective realities and universal truths (Burr, 2015; Crotty, 1998). Scholars critiquing positivism find the dominant approach to be too simplistic, ignoring the various social and cultural features that contextualize human life (Hung & Fung, 2020). For instance, whereas a positivist way of understanding centers on the discovery of Truth through a series of rigid, standardized procedures, social constructionism places an emphasis on interpretation of human interaction (Lit & Shek, 2002). A key feature of understanding in social constructionism is the use of language as a tool for interaction and for interpreting meaning; positivists often minimize the importance of language in their scientific investigations (Lit & Shek, 2002). Additionally, positivists believe truths transcend spatial and temporal contexts, whereas social constructionists situate understanding within specific cultural and historical realms (Lit & Shek, 2002). Finally, positivists view scientific investigation as a strategy used to approach a True understanding of the natural and social world(s), but social constructionism rejects the idea that any one Truth is more accurate

than another and, in fact, people may construct the meaning of ‘truth’- even when regarding the same concept- in different ways (Crotty, 1998; Lit & Shek, 2002). These differences begin to describe some features important in the birth of the social constructionist perspective as a new epistemological orientation.

Because social constructionism emerged from several disciplines, there is no one definition for the perspective. Instead, each discipline may emphasize different elements of social constructionism in their work (Hung & Fung, 2020). Burr (2015) defines social constructionism as any approach emphasizing at least one of the following four features: (1) criticism toward objectivist views of reality, (2) specification of historical and cultural contexts of knowledge (3) recognition of social interaction’s role for sustaining knowledge, and (4) attention toward the relationship between knowledge and social action. These features may be emphasized in one of two forms of social constructionism: macro social constructionism and micro social constructionism (Burr, 2015). Macro social constructionism refers to the use of this theoretical approach to understand cultural discourses and power relations, whereas micro social constructionism refers to the application of social constructionism in understanding individual identity formation or interpersonal interactions (Burr, 2015). This duality- the use of theory at the macro or micro level depending on the focus of a research study- is not a new concept in social research. In sociology, theorists often distinguish whether their theoretical approach is intended to investigate at the societal (macro) or at the individual (micro) level (DeCarlo, 2018). Burr (2015) argues that perpetuating this dichotomy is the largest criticism for using the social constructionist approach, especially when the research topic is identity or the self. Whereas psychologists may adopt a use of micro social constructionism to emphasize the role of the individual in the construction of self, sociologists will study the same phenomena while

emphasizing the role of the society in the construction of the self via macro social constructionism. While this may not seem problematic at first, growing variability in the theoretical application of social constructionism leaves room for ambiguity regarding rigorous use of the theory as a framework for investigation.

Therefore, when claiming to use social constructionism as a theoretical foundation in research, it is important to be transparent and to clarify the researcher's intentions and adapted uses of the theory for their study. The present study does not focus on the individual or on the societal levels of influence on self-development alone, but rather seeks to explore the ways in which the two interplay in the creation and maintenance of self-perception among AYA with cancer. In studies which concern the relationship of individual and society, Burr (2015) suggests looking back on the early work of Berger and Luckmann (1966) who acknowledge a dialectical relationship between the concepts, whereby society is a human product *and* human is a societal product. This study is not only concerned with the individual's subjective self-perception, but also with objective meanings of social interaction online. Therefore, this study's application of social constructionism adheres most closely to the work proposed by Berger and Luckmann (1966).

Berger and Luckmann's (1966) Social Constructionism

Berger and Luckmann redefined the sociology of knowledge in their publication, *The Social Construction of Reality* (1966). Their argument removes the dichotomy of understanding human nature as being either sociologicistic or psychologistic. Instead, they examine how the individual and society co-construct objective and subjective realities within social contexts (Berger & Luckmann, 1966). Their theory of a socially constructed reality does not negate the idea that an objective reality exists. It instead describes the ways that social interaction produces

and maintains an objective reality, denying any reality that pre-exists outside the realms of human interaction and thought (Berger & Luckmann, 1966). In other words, the dialectical relationship between society and individual observes both objective and subjective reality which must be examined together in order to generate knowledge about a given phenomenon. Importantly, acknowledging an objective reality means accepting that people cannot freely construct any reality they choose; they are limited by the reality that is accepted as meaningful by their predecessors (Burr, 2015). However, people do maintain some agency in the construction of society as objective reality. One's thoughts and behaviors constitute society as subjective reality which stimulates the ways in which objective reality is shaped and passed onto future generations.

The construction and maintenance of objective reality and subjective reality occurs through three processes: externalization, objectivation, and internalization (Burr, 2015). Each of these three processes require social interaction and occur simultaneously. Externalization is a process where humans produce expressions, tools, language, symbols, or values to represent thought and action (Berger & Luckmann, 1966). From the moment that someone interacts with another person in a face-to-face setting, they interpret that persons' expressions with subjective meaning-making and negotiated understanding. Over time, patterns of similar expressions are given meaning and extended into typical social structures defining that expression.

Externalization occurs in the moment that humans exude the expression, use language, or other symbols to represent the things that are meaningful across time and space, outside of the initial face-to-face interaction, and beyond the here and now (Burr, 2015). Another process of a dialectic society is objectivation. In objectivation, shared meanings from externalization are transferred and applied by many in new instances that differ entirely from the initial instance

which produced the meaning (Berger & Luckmann, 1966). Over time, there is a collective agreement of a reality that is experienced by many, taken for granted, and lacks awareness that the meaning of that reality was initially constructed by humans (Burr, 2015). Language is often the tool utilized for objectivation, because language is a system of shared definitions that perpetuate patterns of meaning, but language can be detached from situations and reapplied to new moments endlessly. These patterns of meaning also undergo an individual process of internalization. Internalization is the process of an individual accepting the externalized world, as represented through objectivations, as an objective reality (Berger & Luckmann, 1966). These internalized views of reality are then organized and passed down to following generations through the processes of socialization (Burr, 2015). Ultimately, through externalization, objectivation, and internalization, Berger and Luckmann (1966) contend that neither individuals nor society are sole producers of reality, but rather there is a system of reality construction and adoption which is upheld over time.

Social Constructionism, Online Self-Presentation, and Self-Perception in AYA with Cancer

Externalization, objectivation, and internalization are all processes of either collective or individual meaning-making. While externalization and objectivation are more collective meaning-making experiences central to society as an objective reality, internalization is a subjective process of understanding one's own and others' experiences and of participating in the collectively meaningful social reality (Berger & Luckmann, 1966). Initially, it may seem that a study examining self-perception should focus on individual levels of meaning-making. Indeed, the construct of self-perception is subjective, defined as one's evaluation of the self. However, a social constructionist perspective argues that self-perception is only part of subjective reality, which is, "always dependent upon specific plausibility structures, that is, the specific social base

and social processes required for its maintenance” (Berger & Luckmann, 1966, p. 154-155). In other words, the individual can only evaluate themselves according to the structures given to them by the social bases and processes that they are familiar with and that they have internalized as part of an objective reality. Thus, in order to generate knowledge about self-perception in AYA with cancer, it is first important to understand the features of objective reality that are central to the social structures contributing to the self-evaluation process among AYA with cancer.

Social constructionism serves as the macro-theory for this study because it guides the approach for understanding self-perception in AYA with cancer through an initial exploration of the objective reality constructed via social interaction (self-presentation) on social media. Because language, signs, and symbols are important tools for the construction of knowledge in everyday life, the researcher will explore the language, signs, and symbols that are externalized and then objectivated to convey an objective reality of shared meaning within social media interaction. For an example, consider Berger and Luckmann’s (1966) description of externalization and objectivation of a weapon. They state that, “a weapon may have been originally produced for the purpose of hunting animals, but may then (say, in ceremonial usage) become a sign for aggressiveness and violence in general” (Berger & Luckmann, 1966, p. 35). In this way, the weapon is both a tool produced by humans for a specific meaning and also an objectivation of human subjectivity associated with that tools’ use in future and evolving instances. Now consider the same concepts of externalization and objectivation of language or symbols within the context of social media: what can be said about how these processes extend to the use and understanding of the meaning of ‘likes’ or ‘comments’ given in response to posts shared online? When initially engineered, the purpose of a ‘like’ may have been intended to

serve as a platform feature indicating one person's acknowledgement or support of another person's social media post. But with time, the meaning of that 'like' has since transformed from an externalization of human thought and action (a sign of support) to an objectivation of human subjectivity. The meaning of a 'like' now extends beyond the boundaries of a single post. It now seems to indicate a more profound sense of overall approval and positive evaluation of the other person's identity (Lowe-Calverley & Grieve, 2018).

Berger and Luckmann (1966) state that when there are radical changes in social structure there may also be changes in subjective psychological reality. When applying these ideas even further to the subject of the current study, one may wonder whether a cancer diagnosis, which indeed alters social structures, also alters the objectivated meanings of social interaction online or the subjective reality of self-perception. Berger and Luckmann (1966) further contend that successful socialization is indicated by a "high degree of symmetry between objective and subjective reality (as well as identity, of course)" (Berger & Luckmann, 1966, p. 163).

Accordingly, when a goal exists to promote successful socialization among AYA despite the psychosocial disruptions associated with a cancer, there must also exist an inquiry into the interrelationship between social and individual meaning-making. An inquiry into such a broad topic requires narrowed focus on the specific contexts of social interaction important for sustaining knowledge. For the population of the current study, the social media, peer, and hospital contexts are most salient for investigating meaning-making related to social interaction and self-development. Taken together, these key theoretical features of social constructionism shape the current investigation of the AYA with cancer's objective and subjective realities related to self-presentation on social media and self-perception. While social constructionism serves as the macro-theory guiding the epistemological perspective to this study, further

theoretical justification is needed to support the selection of social media, peers, and the hospital as the relevant social structures or contexts important for understanding the AYA with cancer's objective and subjective realities related to self-perception.

Mid-level Theory: Bronfenbrenner's Ecological Systems Theory of Development

The purpose of a mid-level theory, also known as a middle-range theory, is to serve as an intermediate theory between the most general (macro) and more specific (micro) theories framing a social research study. Conceived by sociologist Robert Merton, mid-level theories are meant to guide social inquiry in an empirical manner, identifying the constructs that are important to a research study and may be too abstract to identify through macro-theory, but are also not too particular so as to close off the inquiry from further conceptualization (Merton, 1949). Whereas social constructionism serves as the macro-theory situating the general approach to knowledge generation through investigation of objective and subjective realities, ecological systems theory serves as the mid-level theory contextualizing the empirical spaces and relationships for investigation which are most salient to the research participant.

One developmental theory aligned with the work of social constructionists, is Bronfenbrenner's (1979) ecological systems theory. Similar to the development of social constructionism, Bronfenbrenner's ecological paradigm arose in direct contrast to formerly established psychological theories of development (Bronfenbrenner, 1994). While grand developmental theories align more closely to objectivist epistemological frameworks, uncovering universal trends in development, Bronfenbrenner's developmental theory considers the interactions of the individual and the society as an ecosystem, in which cultural and historical specificity cannot be ignored. Bronfenbrenner (1994) suggests that human development is best

understood when the growth of an individual is considered within a comprehensive ecological system.

The ecological systems theory of development is characterized by its nested model of ecosystems surrounding the developing individual. There are five key environments that serve as contexts for human development, from the level most central to the individual to the level most external from the individual are the microsystem, the mesosystem, the macrosystem, the exosystem, and the chronosystem (Bronfenbrenner, 1994). Each level of the ecosystem is comprised of settings, interrelations of settings, social structures, cultural institutions, or other properties which serve in the development of a single individual (Bronfenbrenner, 1977). The microsystem consists of settings, “with particular physical features in which the participants engage in particular activities in particular roles (e.g. daughter, parent, teacher, employee, etc.) for particular periods of time” that make up an individual’s immediate environment (Bronfenbrenner, 1977, p. 514). Typical examples of settings within the microsystem include home, school, or workplace (Bronfenbrenner, 1977). The mesosystem is the next level of the nested environments. Unlike other subsystems, the mesosystem is not made up of new settings or structures. Instead, the mesosystem contains the interactions between the settings defined within the microsystem. For example, the mesosystem may describe the influence of the interrelatedness between the home and the school environment on a child’s developmental outcomes (Bronfenbrenner, 1977). The exosystem extends from the mesosystem and holds greater social structures relevant to the individual’s development although the individual may not directly interact in a formal way with that structure. Some examples of structures in the exosystem are agencies of government or the mass media (Bronfenbrenner, 1977). The macrosystem is the next level and is a comprehensive system referring to greater cultural,

economic, social, or educational systems and values (Bronfenbrenner, 1977). Although not included in Bronfenbrenner's early works describing the ecological systems theory, the chronosystem was later included in the theory by Bronfenbrenner to acknowledge the system of time containing the chronology of an individual's development (Bronfenbrenner, 1994).

Bronfenbrenner's ecological model of human development is not specific to adolescent development, but his theory is indeed useful in the study of adolescence (Chandrasekaran et al., 2017; Smetana et al., 2006). When ecological systems theory is applied to adolescent development, researchers often examine micro- and mesosystem level interactions (Chandrasekaran et al., 2017; Muuss, 1996). Focusing on these levels of the ecological model for understanding adolescent developmental outcomes is useful because it is within these levels that the most change to adolescent life occurs (Bronfenbrenner, 1994; Chandrasekaran et al., 2017). Given that adolescence is characterized as a time of transition between childhood and adulthood, there are indeed several personal, environmental, and social changes that take place during this developmental period (Smetana et al., 2006). Recall that microsystems are characterized as settings that are most often interacted with by the developing individual. For the developing child, the most influential settings of development may include the family and the home, but these settings may begin to play different roles for the developing adolescent or young adult (Muuss, 1996). The range of settings that an adolescent engages in is increasingly greater than that of a child, and the familial relationships established in childhood often undergo shifts during adolescence (McHale et al., 2009; Smetana et al., 2006). As adolescents gain independence from their family members, they spend more time with peer groups and begin to develop romantic relationships. Additionally, during adolescence and young adulthood, individuals are drawn to new leisure and vocational activities that occupy time and introduce the individual to new

immediate physical settings (McHale et al., 2009; Muuss, 1996; Young, 1983). Acknowledging the significance of these relational shifts is highly important in the study of adolescence (Smetana et al., 2006). For this reason, when researchers evaluating adolescent developmental outcomes frame a study through an ecological systems theoretical lens, they must acknowledge the microsystems most salient to their participant and outcome.

Microsystems of Development for AYA with Cancer: Hospital, Peers, and Social Media

The microsystems serving as important contexts of development for adolescents include family, school, peer group, and workplace (Bronfenbrenner, 1977). While these are the common microsystems evaluated in adolescent research using an ecological systems approach, they are not the only microsystems affecting adolescent development. Among studies regarding self-development in adolescents, families, peers, and school are substantial in predicting associations with self-views in adolescence (DuBois et al., 1996). However, as discussed above, changes in adolescence introduce many new possible interpersonal settings, like sports teams or even digital media, which may be contextually relevant to adolescent developmental outcomes (Muuss, 1996; Johnson, 2010). A cancer diagnosis during adolescence can further disrupt the most common interpersonal contexts encountered by an adolescent. During treatment for cancer, AYA are unable to maintain typical school experiences, report changes in their friendships, and face limited opportunities to engage in normal leisure activities (Zebrack, 2011). These contextual changes are important to consider when identifying the microsystems important in evaluating developmental outcomes in this population. The current study identifies the hospital, peers, and social media as important interpersonal contexts for development of AYA with cancer (see Figure 2).

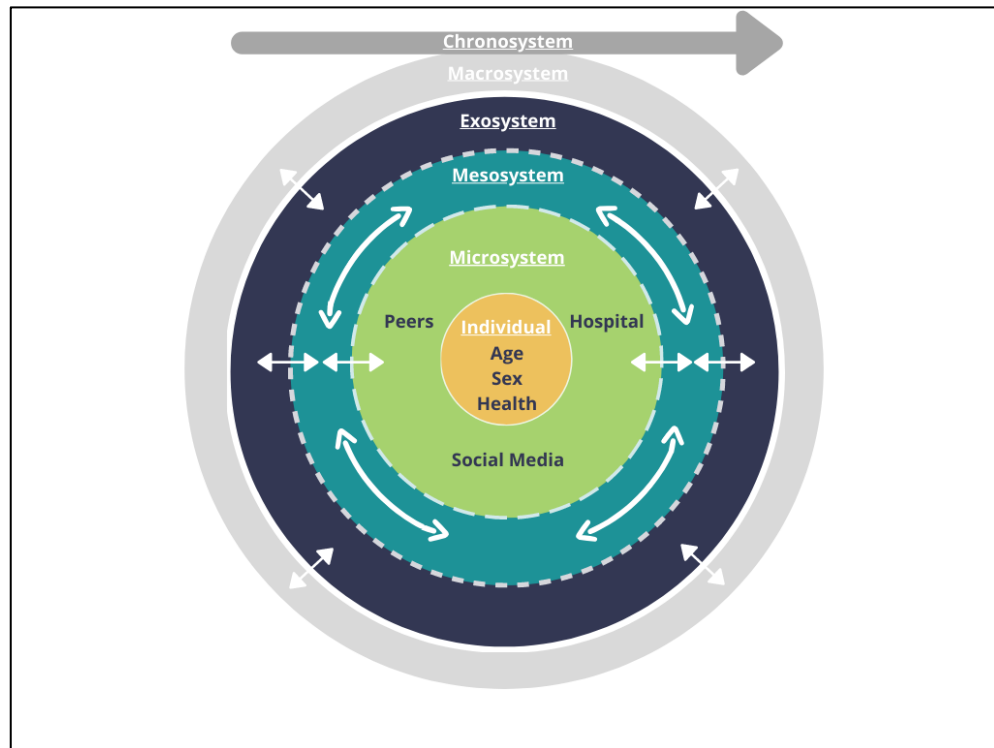


Figure 2. *The Ecological Model of Development for AYA with Cancer*

The Hospital. Existing literature applying ecological systems theory to developmental outcomes of youth with cancer is limited. In families of children with chronic illness, Kazak (1989) discusses the importance of utilizing a systems perspective that evaluates the roles of social networks and medical systems in developmental outcomes. In fact, the illness itself may be viewed as a microsystem of development in pediatrics (Kazak et al., 1995). Rather than examining the illness itself, the current study identifies the hospital as a microsystem of development for AYA with cancer. The reason for this, is that AYA patients identify the healthcare setting among the most influential interpersonal contexts affecting their cancer experiences during treatment (Juth, 2016). Some literature interprets the placement of the hospital within the mesosystem rather than as a microsystem (D’Olivo et al., 2018). This perspective emphasizes the organizational system of the hospital as a place for interrelationships between other microsystems. But the current study views the hospital more similarly to the role

of the school for healthy youth. During active treatment, AYA with cancer must frequently visit the hospital and endure several social interactions within this context (Juth, 2016). Additionally, it is within the healthcare setting that youth with chronic illness often directly encounter illness-related stressors that impact development (Hosek et al., 2008). Whereas school is the most common context for social experiences in healthy youth, the hospital becomes an environment of social interaction for the AYA with cancer (Kalaurachchi et al., 2020). During treatment, the hospital becomes more secondary to the home environment than the school and can therefore serve as a microsystem for the developing AYA with cancer.

Peers. Peer groups are often reported within the microsystem level of the ecological systems theory for research related to adolescent development (Bronfenbrenner, 1977). Direct face-to-face relationships with peers grow throughout adolescence, and thus peer groups stand out as a key microsystem for adolescent development (Muuss, 1996). Compared to healthy AYA, AYA with cancer encounter several stressors and disruptions to their peer groups (Zebrack, 2011). These challenges may alter the ways in which peers serve as a context for developmental outcomes in AYA with cancer. Specifically, peer group interactions (or lack thereof) during cancer treatment may be a source of social support or a source of social isolation. Depending on how these interactions are characterized, the context of peers may influence developmental outcomes differently. Importantly, AYA with cancer report differences in types of peer groups. In addition to a community of healthy friends, AYA with cancer grow a community of peers within the cancer community (Kaluarachchi et al., 2020). The interactions of an AYA with cancer within the peer group setting is certainly an important context for development.

Social Media. Social media platforms are among the most prevalent spaces for adolescent social interaction (boyd, 2014). Most AYA in the United States today report using at least one social media platform (Pew Research Center, 2018a). Despite their frequent engagement in online activity, there are few studies that exist which place social media as a microsystem of development for adolescents. In fact, rather than place social media in an already existing level of the ecosystem, some researchers actually propose creating an entirely new level, called the techno-subsystem (Johnson & Pupilampu, 2008). Johnson and Pupilampu (2008) created the techno-subsystem as a level intermediating the individual and the microsystem, whereby the digital technology utilized (telephone, computer, internet, etc.) served as a means of communication between the individual and the microsystem. However, with an assessment of the frequency of internet use among youth, Johnson (2010) later identified that youth use the internet most often within the microsystems of home and school and that this use is what is associated with certain social and emotional developmental outcomes. This direct interaction with the internet was then theoretically re-conceptualized by Johnson as a techno-microsystem (Johnson, 2010). More recent research using Johnson's (2010) framework further explore the role of a techno-microsystem and reveal that it is indeed important to define the characteristics of the contexts within which technology is used, like the family dynamics in the home, when exploring the role of technology on youth development (Konca, 2021). When social media serve as a socialization agent, it is appropriate to place it within the microsystem of development (Cala & Soriano, 2014). For the purpose of the current study, social media is evaluated as a platform for peer maintenance, activity engagement, and direct interaction with others and is thus supported as a system within the microsystem of the developing AYA with cancer.

Proximal Processes of Self-Development in AYA with Cancer

Perhaps even more important than defining the microsystems relative to the developmental outcome of the study, is the attention given to the mesosystem, or the linkages between those microsystems (Bronfenbrenner, 1977). In mesosystem analysis, researchers can explore the quality, frequency, and impact of the interactions of several microsystems on a given developmental outcome (Muuss, 1996). These analyses indicate the strengths or weaknesses of the mesosystem and provide insight toward any conflicts that may hinder positive outcomes. For example, research on children's adjustment to school indicates more positive outcomes, like initiative and achievement, when the family and the school communicate well with one another (Muuss, 1996). This example highlights how a rich interrelationship between the microsystems of family and of school contribute to a positive developmental outcome in children. These interrelationships become more complicated in adolescence, when adolescents are more likely to encounter conflicts in their social roles in different contexts (McHale et al., 2009; Muuss, 1996). For example, if peer groups glamourize risky behavior like underage drinking, while families condemn that type of behavior, the adolescent will face a conflict between fulfilling their role in their peer group microsystem and in their family microsystem. At an interaction level, the adolescent will encounter divergent peer-family value systems that may impact adolescent engagement in risk taking behavior (Muuss, 1996). Therefore, evaluating the interactions that impact the mutual interrelationship between different microsystems is most significant for understanding developmental outcomes in adolescence.

Appropriate application of Bronfenbrenner's ecological systems theory in social research thus requires more depth than simply citing the value of considering unidirectional contextual influences on development (Tudge et al., 2009). While early descriptions of Bronfenbrenner's ecological systems theory admittedly focus on identifying contextual factors at various levels of

an ecosystem that are influential to human development, the usefulness of this theory for research purposes lies in the researcher's ability to distinguish which interactions are a function of the nature of the developmental outcome under consideration (Tudge et al., 2009). In other words, human development is not an outcome of contextual influence alone, but rather a growth that takes place through, "processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate environment. To be effective, the interaction must occur on a fairly regular basis over extended periods of time" (Bronfenbrenner, 1994, p. 38). Bronfenbrenner (1994) refers to these enduring interactions in the immediate environment as 'proximal processes.' The effects of proximal processes are often more significant to explore in the study of adolescent development than the effects of context on developmental outcomes alone (Muuss, 1996). For this reason, the current study identifies the settings within the microsystem that are contextually relevant for developmental outcomes of AYA with cancer, but further seeks to evaluate the impact of the interactions between these settings on development of self-perception rather than the impact of each settings' individual role in that outcome. Simply put, this study characterizes the hospital, peers, and social media as settings defined in the microsystem of an AYA with cancer and seeks to understand how peer/social media, social media/hospital, and peer/hospital interactions contribute to the development of self-perception among AYA with cancer.

Further theoretical justification is required to specify the types of interaction occurring within the mesosystem and to identify the variables that may motivate or hinder these interactions. For example, although the mid-level theory can support the selection of examining interactions within the hospital, peer, and social media settings, not enough literature exists to

propose how these interrelationships affect self-perception in AYA with cancer. It is possible that the interactions between these systems provides a context of support and positively contributes to self-perception in AYA with cancer, or it is possible that the roles that the AYA with cancer experience within each of these settings conflicts with the others and negatively impacts self-perception. Ultimately, further theoretical support is needed within a micro-lens to speculate on the behaviors which will characterize these relationships. For the first component of this study, Goffman's theory of self-presentation (1959) guides the interpretation of AYA-reported experiences about their social interactions within the hospital-peer-social media system. From these perspectives, Harter's theory of self-development (2012b) was utilized to identify illness concepts affecting these interactions and, ultimately, the self-perception of AYA with cancer.

Social Interaction and Self-Development in AYA with Cancer

Drawing upon the macro- and mid-level theories framing the epistemological and theoretical approach to the current study, two additional micro-theories are utilized to specify the conceptual framework of investigation. Given that the current study is designed in two components, one part qualitative and one part quantitative, two micro-theories are needed to justify the concepts explored within each part of the study and to support the direction of each research question. The overall goal of the study is to understand self-perception in AYA with cancer. Self-perception is a developmental outcome indicating the way one evaluates themselves (Harter, 2012b). Social constructionism and ecological systems theory recommend evaluating the role of social interaction within interrelated contexts for predicting developmental outcomes in AYA. So, in order to understand self-perception in AYA with cancer, the present study must first understand the social interactions which occur within the interrelated hospital, peers, and social

media spaces. Therefore, the initial qualitative component of the current study explores a specific type of social interaction that takes these contexts into consideration: self-presentation according to Goffman (1959). However, this information about self-presentation does not comprehensively describe the development of self-perception among AYA with cancer. The researcher must also acknowledge the illness variables that may motivate and/or hinder the self-presentation of an AYA with cancer. Some potential illness variables playing this role are identified through a literature search, but the qualitative data from the first phase of this study more clearly identified these. In the quantitative phase of this study, the researcher intended to evaluate the impact of these illness variables as moderators between self-presentation and self-perception. However, due to limited data collection some adjustments were made to the quantitative phase of this study (see more in Chapter 4). Harter’s (2012b) depiction of self-development in AYA provides support for the quantitative investigation. Figure 3 presents a visual representation of the concepts originally planned for evaluation at each phase of this study.

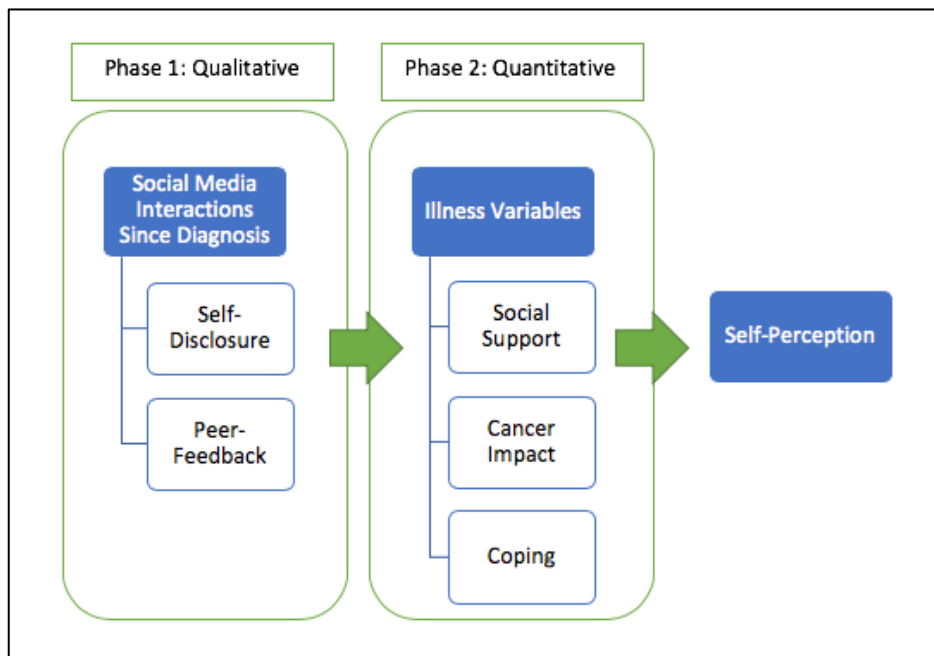


Figure 3. *Conceptual Framework*

Goffman's (1959) Theory of Self-Presentation

In his book, *The Presentation of Self in Everyday Life*, Erving Goffman uses a dramaturgical metaphor to describe the socially interactive process of self-presentation. Goffman says that self-presentation, a process of interaction where an individual expresses and forms their identity, is best understood within a theatrical setting, where life is a stage, people are actors or audience members, and where there is a boundary between the front stage and the backstage (Goffman, 1959). When individuals perform to audiences on the front stage of life, they engage in a specific type of self-presentation called impression management (Goffman, 1959). Impression management is a strategic performance, where an individual makes decisions about what types of expressions of self they can comfortably share with the audience (Leary & Kowalski, 1990). These expressions may be motivated by a desire from the individual to convey an ideal sense of self, a sense of self that is congruent with the version the audience anticipates, or a sense of self that is most accurate with the sense of self that exists backstage (Goffman, 1959). Performances occurring in the backstage are less calculated, less scripted, and while they still have an audience, they are not as judged as the performances done on the front stage (Goffman, 1959). Importantly, “the degree the individual maintains a show before others that he himself does not believe, he can come to experience a special kind of alienation from self and a special kind of wariness of others” (Goffman, 1959, p. 236). Understandably, self-presentation is inextricably linked with self-views. An element that is especially meaningful to this relationship is the feedback that an audience gives to the performer. Audience feedback, which may demonstrate approval or disapproval, given in response to one's performances impact one's identity across both the front and the backstage (Goffman, 1959). The interpretation of feedback

and the impact it has on the self-view then influences future performances and self-development (Goffman, 1959).

What Does Self-Presentation Look Like for Typically Developing AYA?

Self-presentation is an important activity for AYA typical development (Calvin, 2020). As AYA establish independence from their parents, spend more time with peer groups, and participate in school, vocational, or leisure activities, AYA engage in self-presentation with an array of audiences. Today's AYA were born into a digital world, one where television, computers, and social media pre-existed their birth. This means AYA social interaction not only occurs with different audiences, but also across different platforms (Calvin, 2020). Indeed, AYA in the United States interact with peers more in online spaces than face-to-face (Pew Research Center, 2018b) While face-to-face socialization remains important for developing AYA, online social interaction is a significant aspect of AYA life today (boyd, 2014). Online self-presentation differs from self-presentation offline, because performers have more time to devote to selecting, constructing, and editing the images of themselves that they choose to share in order to make specific impressions on others (Stern, 2008). After thoughtfully constructing and sharing the presentation, an individual receives feedback in the forms of likes and comments, which contribute to that person's evaluation of themselves (boyd, 2014). Thus, understanding self-perception among developing AYA today requires attention to AYA self-presentation online.

Self-Presentation on Social Media. In the United States, a majority of AYA use social media at least daily, if not multiple times per day (Pew Research Center, 2018a). AYA often report that their motivations for using these platforms are to maintain friendships (Pew Research Center, 2018b). Social interaction online may also be a space for AYA to practice social skills as is less threatening than face-to-face interactions (Metzler & Scheithauer, 2017). Another

motivation for social media use is identity development and self-presentation (Michikyan et al., 2015; Young, 2013). Social media contain several features which enable thoughtful identity development through self-presentation (Vogel & Rose, 2016). Self-presentation on social media emphasizes the agency of a user to selectively share aspects of themselves that they are comfortable disclosing to others (Valkenburg & Peter, 2011). All AYA activity online is a form of self-presentation but sharing an image of the self is one way that AYA commonly present themselves online (boyd, 2014). The self-presentation performance is the active selection of a photo, the design of the caption, the editing of the image, and the overall control of the content a social media user chooses to share. On Instagram, AYA manage their impressions through managing the content of the photo and utilizing editing features (like filters). AYA also construct captions that correspond to the image they share (Seehafer, 2017). After sharing these images and captions, social media users are able to receive highly responsive and visible feedback, which inform their understanding of an audience's reaction to their self-presentations (Calvin, 2020). These are just a few reasons why social media serve as a unique space for AYA to engage in self-presentation in ways that are meaningful for their self-development.

The Importance of Peer Feedback. AYA social media users respond to posts made by others in the forms of 'likes' and comments (boyd, 2014). As AYA engage in self-presentation, they are thoughtful about the judgements that others will make in response to their post. Among healthy AYA, they report finding social media as a place to engage in open and emotionally expressive self-presentation, due to the level of separation from face-to-face contexts (Calvin, 2020; Walsh et al., 2020). This space is useful for people who want to share distress in the moment that they feel it, and online self-presentation is a means for eliciting support from peers via the feedback they receive (Gibson & Trnka, 2020). But the level of responsiveness from

peers is also important for predicting self-presentation online. People who perceive their online audience to be more responsive in providing feedback are also the people who post more openly online (Walsh et al., 2020). Taking these things into consideration, healthy AYA often consider several factors that motivate their type and timing of online self-presentation.

The perceived judgements of others influence both the type of content a user will share and the frequency of how often they share (Duffy & Chan, 2019; Seehafer, 2017). In order to fulfill social norms, AYA users must not post too often, but must also post enough to remain engaged in social media activities (Seehafer, 2017). With self-presentation goals to seem interesting, well-liked, and attractive (especially in girls) to peers, AYA anticipate their peer's perspectives of the images they share when planning what to post (Yau & Reich, 2019). The norms of peer feedback also make it difficult for AYA to share freely. They report needing to post at specific times of day when they know their friends will be online in order to elicit more likes and feedback (Yau & Reich, 2019). AYA must also edit their images the appropriate amount without going overboard; they want to "give the world a taste of what their life looks like" while leaving the most positive impression (Seehafer, 2017, p. 35). One reason AYA want to share performances online that are positive is because positive self-presentation predicts higher positive feedback from followers (Metzler & Scheithauer, 2017). While feedback from others matter to all individuals, AYA are particularly concerned with their peers' opinions, and thus AYA value 'likes' and comments that their social media audience share in response to their online self-presentation (Calvin, 2020).

Because peer influence is most intense during adolescence, it is understandable that the desire to obtain positive peer judgement has a strong impact on the type of self-presentation that AYA engage in online. Indeed, 'likes' are a type of peer feedback online which are particularly

rewarding to AYA. In a study looking at the brain function of AYA, the neural regions involving reward processing activated more when AYA looked at Facebook posts with more ‘likes’ compared to posts with fewer ‘likes’ (Sherman et al., 2016).

For developing AYA today, self-presentation is largely made up of sharing images and receiving feedback on social media. Participating in social interaction online is a typical aspect of AYA life and examining the features of that interaction is important for understanding self-development. Particularly, exploring self-presentation through the user’s image-sharing and interpretation of peer feedback may provide key information regarding AYA self-perception today.

What Does Self-Presentation Look Like for AYA with Cancer?

Self-presentation among AYA with cancer is undoubtedly different than self-presentation among typically developing AYA. Surely, some similarities in self-presentation online remain the same. For instance, AYA with cancer report using social media during treatment as a way to maintain friendships (Daniels et al., 2021). Additionally, AYA with cancer are thoughtful about the role that peer feedback play and consider this before sharing content on social media (Daniels et al., 2021). But a key difference between healthy AYA and those with cancer, is that AYA with cancer must consider how to incorporate the self-presentation of a cancer diagnosis into their online interactions, or how to avoid it entirely.

In offline interactions, AYA cancer survivors reflect that there are several reasons they may or may not be motivated to disclose their cancer diagnosis to others. When they do choose to disclose, it is with goals to feel understood, achieve support from others, and feel accepted in this aspect of themselves (Easley, 2019). They report common hinderances to disclosure as fear of judgment, rejection, or receipt of unwanted attention (Easley, 2019). But AYA survivors may

have more control over whether or not to disclose information about their cancer experience than AYA on treatment for cancer, whose effects from the illness are more immediately apparent. AYA with chronic illness, including cancer, report that disclosure is one of the most challenging parts of being diagnosed with a chronic illness (Woodgate et al., 2020). They describe illness self-disclosure as a complex process where they sometimes find it to be helpful in giving them a sense of control, but where they also find they are doing it just to benefit others (Woodgate et al., 2020). Disclosure among AYA with chronic illness is more common with peers who can relate to having an illness, and the reason for not disclosing is fear of being seen as different (Barnett et al., 2014; Kaushansky et al., 2017). Finally, when AYA with chronic illness do choose to disclose about their illness, they limit how much information is shared and report that it is staged, thoughtful, and exhausting (Woodgate et al., 2020). Given that social media may serve as a less threatening environment for self-presentation than face-to-face interaction among healthy AYA (Metzler & Schiethauer, 2017), the role of social media in self-presentation among AYA with cancer is curious.

Self-Presentation on Social Media among AYA with Cancer. Some literature begins to explore the role of online platforms for AYA with cancer. AYA with chronic illnesses report using social media as a way to maintain contact with friends and to provide updates to others about their illness experiences (Liu et al., 2015; Merolli et al., 2013). But this literature most often evaluates AYA patients' use of online patient communities or illness-specific webpages, rather than examining their self-presentation on more commonly used platforms, like Instagram or Snapchat. But the purpose for self-presentation among AYA with cancer online, despite the platform, remains the same: it is a place for expression, socialization, and to receive feedback from peers. Within cancer communities online, AYA survivors are seen processing information

about their diagnosis (Keim-Malpass et al., 2016). AYA are expressive about how they deal with cancer, and they use these online groups to meet the need of identity development, especially as they process the transitions between life with and after cancer (Love et al., 2012). Even when processing difficult information, AYA present their experiences in the frame of humor, often to lighten bad news of relapse or progression (Keim-Malpass et al., 2016).

However, a review of the publications on AYA cancer patient and survivor social media use reveals a dearth of literature regarding AYA social media engagement on naturalistic sources, despite younger AYAs reporting feeling like Facebook is a desirable source for peer-to-peer support programs (Chou & Moskowitz, 2016). Regarding online interventions supporting AYA with cancer, Chou and Moskowitz (2016) importantly state, “If you build it, they may not come, so go where they are” (Chou & Moskowitz, 2016, p. 90). This statement acknowledges the importance of building online interventions to support the emotional and informational needs of AYA cancer patients but emphasizes the importance of better understanding the use of more commonly used platforms than inventing new platforms to meet these needs.

Some literature does indicate that online interventions promoting cancer-related self-presentation is useful for AYA with cancer. In a study by Pereira et al. (2019), AYA cancer patients and survivors were asked to create a video reflecting on their cancer experience in the style of a YouTube video. Analysis of these videos revealed that posting online narratives can be a helpful tool for processing the illness experience and serves as a way to make sense of their diagnosis in a way that is easily accessed by peers (Pereira et al., 2019). This study contributes the idea that self-presentation online about the cancer experience leads to the process of reflection and meaning-making but does not evaluate this process as it naturally occurs on patient’s self-selected social media platforms. Many AYA cancer survivors report wanting more

information about how to talk about cancer with friends and family (Kent et al., 2013). Given that normative social media are a space where communication naturally occurs among AYA with friends (boyd, 2014), more support should be provided to AYA with cancer regarding their cancer self-disclosure on such platforms.

Although not among cancer patients, one study does explore the use of normative social media sites for self-presentation among chronically ill teenagers. In this study, the researchers found that AYA with chronic illness report using their social media sites as a place to stay ‘normal’ and to avoid discussing their diagnosis and treatment (van der Velden & El Emam, 2013). However, this study was conducted in 2013 and it is possible that the norms of social media use for self-expression have since evolved (van der Velden & El Emam, 2013).

Regardless, AYA with chronic illness report managing others’ impressions by protecting their image via promoting an image that is healthy and strong in order to keep their hospital life separate from their life viewed by healthy peers (van der Velden & El Emam, 2013). This study importantly contributes information to the current investigation by offering insight as to some motivations for self-presentation, or lack thereof, of hospital images by AYA with chronic illness. It is curious, however, how the role of such a visible and defining diagnosis like cancer changes these motivations. For instance, it is plausible that it is difficult for an AYA with cancer to conceal their diagnosis in self-presentations online than an AYA with a chronic illness that is less disruptive to their daily routine and physical appearance.

In a study done prior to the development of social media platforms that are utilized today, Suzuki and Beale (2006) reviewed personal blogs of cancer patients and found that the web is indeed a source for AYA with cancer self-presentation. Most often these sites were used for sharing information about their cancer experience and for enhancing interpersonal connection.

They expressed themselves, shared external links to cancer information, statistics, desire for people to understand their experience (Suzuki & Beale, 2006). The findings from this study revealed how web blogs are useful for examining AYA perceptions of illness via the messages the user shares with others which represent their perspectives (Suzuki & Beale, 2006). However, this study was conducted prior to the growth of social media that is more commonly used today, where sharing images is a large part of online social interaction. Given the sensitivity of AYA with cancer to body image (i.e., Larouche & Chin-Peuckert, 2006), more research should explore self-presentation on contemporary social media sites.

To date, only one recent study goes beyond examining the reasons for using normative social media and instead examines the ways in which AYA with cancer consider their self-presentation on normative social media platforms (Marôpo & Jorge, 2017). In this work, and similar to the findings from literature on healthy AYA, AYA with cancer admit thinking a lot about their self-presentation on social media during treatment. They want to avoid seeming attention seeking and they also do not want to be viewed in an overly positive light, as a hero (Marôpo & Jorge, 2017). When they do share about their cancer experiences, they report that they feel they are seen as examples of courage. For this reason, many AYA with cancer feel more comfortable sharing information after they have recovered from their illness (Marôpo & Jorge, 2017). While this study provides insight into the self-presentation of AYA with cancer on social media, more research is needed about how patients who are actively on therapy present themselves online and how those presentation strategies relate to self-perception.

The Role of Friends and Peers for AYA with Cancer Social Media Interactions. The role of friends and peers are important to AYA with cancer. In literature that examines the role of friendships and peers, friends are defined as healthy friends of AYA with cancer, whereas peers

are other AYA with cancer. AYA with cancer report that their healthy friends are important for their coping with treatment. Healthy friends encourage AYA with cancer to do activities that were typical for their pre-cancer selves and help distract them from challenges associated with diagnosis (Kaluarachchi et al., 2020). Cancer can also make people feel closer to their friends, as going through the experience reveals information about friendships and further solidifies already strong friendships (McDonnell et al., 2020). Unfortunately, healthy friends can also contribute to an AYA with cancer feeling like others have a lack of understanding about their cancer experience or that they are not genuine and overly supportive (Kaluarachchi et al., 2020). Cancer peers, on the other hand, meet AYA cancer patients' needs in these areas. They are able to relate to their illness experiences and provide a unique form of support (Kaluarachchi et al., 2020).

AYA with cancer are known to have social and informational needs that are unmet (i.e., Kent et al., 2013), but as AYA with cancer interact with other cancer peers online, they provide informational, social, and emotional support to one another (Chou & Moskowitz, 2016; Keim-Malpass et al., 2016; Love et al., 2012). Within the cancer community, a content analysis of cancer-related posts on *Imgur* demonstrated mostly supportive comments from peers (Hale et al., 2020). Less is known about the role of healthy friends in online interactions for AYA with cancer. Some AYA share perspectives consistent with the literature regarding the role of friends offline, such that interacting with healthy friends on social media provides a sense of normalcy, but also feels overly supportive or superficial at times (Daniels et al., 2021). AYA with chronic illness spend more time on the internet at the hospital than at home (van der Velden & El Emam, 2013) so it is important to further examine the interactions with friends and peers online for AYA on active treatment. Finally, whereas online patient communities are specific in setting a stage for an audience of cancer peers alone, normative social media is a place where several

communities of friends and peers merge together (van der Velden & El Emam, 2013). Managing self-presentation across multiple audiences may be challenging for any AYA, let alone for an AYA who experiences different reactions from friends and from peers. Finally, only one study examines audience response related to the type of self-presentation shared on a normative platform, Twitter. The study revealed that when cancer-related messages were too detailed, sad, and angry, they were engaged with less often than when presentations about cancer used humor, positivity, or hope (Myrick et al., 2015). These findings further suggest that the type of self-presentation done by cancer patients may receive different levels of feedback online (Myrick et al., 2015). Further support is needed to advise AYA with cancer regarding their social interactions and self-presentation on social media.

Harter's (2012b) Theory of Self-Perception

In Susan Harter's (2012b) book *The Construction of Self: Developmental and Sociocultural Foundations*, she reviews years of research regarding self-development from childhood through emerging adulthood. Importantly, and consistent with this study's epistemological roots in social constructionism, Harter's work considers both the cognitive and social constructions of self, and her work serves psychologists, sociologists, anthropologists, and medical professionals (Harter, 2012b). Her approach to theorizing self-development considers cognitive, social, cultural, and historical roots of studying the self, and thus adopts a broad view of self-development.

Harter (2012b) organizes her understanding of self-development in two ways: the developing self as a cognitive construction and the developing self as a social construction. As a cognitive construction, Harter evaluates the ways in which individuals conceptually organize their self-representations. Compared to other developmental theorists like Piaget or Erikson,

Harter views the development of self-representations as a continuous process rather than one which progresses through stages (Harter, 2012b). Within this continuous process, Harter (2012b) describes the roles of differentiation and integration, which are one's ability to differentiate self-characteristics from others and in different contexts, and one's ability to integrate aspects of the self that further construct a generalized self (Harter, 2012b). For instance, over time, someone can differentiate their ideal self from their perceived self or even acknowledge multiple self-representations in different settings (Harter, 2012b). Further, someone can integrate an ability, like "skilled in singing" to a broader conceptualization of "musician" (Harter, 2012b).

In addition to aspects of continuous cognitive development that inform self-development, there are elements of socialization which also inform self-development. Harter (2012b) says the sociocultural context of an individual's development is particularly important for the content and valence of one's self-representations. For instance, the attention and feedback that one receives from other people in their environment informs their perspectives of themselves. Interpersonal relationships are key for self-development because they demonstrate responsiveness, assurance, and judgments that contribute to the construction of the self (Harter, 2012b). Larger society also plays a role in sharing norms and values that guide the "socially implanted self" (Harter, 2012b, p. 13). Meaning, individuals who defy norms or standards may perform false self-representations to meet expectations despite those behaviors differing from the actual self (Harter, 2012b).

The study of self-development is complex. Many researchers are concerned with identity discrepancies between a true, authentic self and a false, or ideal self. For the purpose of the current study, the definition of self that is of interest is the self-perception, which is defined as the way one evaluates themselves (Harter, 2012a). The current study is not concerned with

teasing out the points of whether that self-perception regards an authentic or a false self, but rather how people perceive themselves to be across several domains (Harter, 2012a).

Self-Perception in Typically Developing AYA

Cognitive and social development occurring during adolescence and young adulthood makes self-perception a particularly interesting topic to explore within this age group.

Cognitively, AYA are able to think hypothetically about the outcome of any given situation and can take others' perspectives to inform their decision-making and behavior (Harter, 2012b). They AYA can engage in abstract thinking about the self which contributes to their ability to reconcile opposing aspects of the self into a more stable general self (Harter, 2012b). For example, and AYA may grapple with a question of how they can be both a happy person in some instances and a sad person in other instances and come to the conclusion that they are an emotional person (Harter, 2012b). Socially, adolescents are both increasingly more independent from their families while also more integrated into peer networks, which are very active online (Spies-Shapiro & Margolin, 2014). On one hand, adolescents seek to distinguish themselves as unique individuals. On the other hand, adolescents engage in social comparison and seek to belong in a group of peers (Harter, 2012b). As adolescents consider the varying perspectives of peers and of others, they begin to adjust their behaviors in different contexts to meet their goals with that group of individuals. These different performances are sometimes referred to as the adolescents' construction of "multiple selves" (Harter, 2012b). When adolescents are aware of these constructions, they confront an identity development issue, where they feel distressed that their self-presentations are not congruent across audiences. With time, adolescents learn that alterations in self-presentation is normal and it is not inauthentic to enact different parts of a self, depending on the context and audience they face (Harter, 2012b).

Self-perception is an interesting unit of focus for the current study, because it is a multidimensional construct; it involves both one's objective descriptions of competence in certain domains, as well as their subjective evaluations of competence in the same domains (Harter, 2012a). It is easy for adults to accept that an individual may think about themselves differently in different areas of life, for instance at work versus at home, but Harter (2012a) investigates how children, adolescents, and emerging adults engage in this self-evaluation with the development of her Self-Perception Profile (Harter, 2012a; Harter, 2016) for each age group. For the adolescent and emerging adult age group, Harter identifies nine different domains which are important for the developing AYA's self-perception. The first eight domains are scholastic competence, social competence, athletic competence, physical appearance, job competence, romantic appeal, behavior conduct, and close friendship (Harter, 2012a; Harter, 2016). The final domain is global self-worth, which is evaluated separately as a more comprehensive indicator of self-evaluation (Harter, 2012a).

Self-Perception in AYA with Cancer

AYA with cancer experience several life disruptions which are in direct opposition to their developmental goals (Docherty et al., 2015; Zebrack, 2011). Typically developing AYA are focused on growing and/or deepening their peer and romantic relationships, establishing a sense of financial and social independence, managing scholastic competence, entering the workforce, and evaluating their physical appearance (Harter, 2012b). Each of these developmental tasks are interrupted by a cancer diagnosis (Warner et al., 2016; Wong et al., 2017; Zebrack, 2011). Treatment from a cancer diagnosis can impact AYA cognitive functioning, decision making, and interrupt the school or work routine (Docherty et al., 2015; Warner et al., 2016). Further, AYA with cancer need to adhere to strict treatment regimens, which are an adjustment and can

contribute to feelings of loss of control (Docherty et al., 2015). Additionally, AYA with cancer experience several social issues, including delayed time in establishing independence from caregivers and interrupted peer relationships (Warner et al., 2016). AYA with cancer report feeling social isolation from treatment which extends into survivorship, meaning feelings of social isolation are not only due to the lengthy or frequent hospital stays during therapy (Docherty et al., 2015). Finally, AYA with cancer experience several physical appearance changes such as hair loss or weight fluctuations as a result of treatment (Larouche & Chin-Peuckert, 2006). Sometimes, AYA with cancer experience negative reactions from healthy friends related to their appearance changes (Docherty et al., 2015). Thus, the ways in which these changes affect perceived body image also negatively impacts relationships with healthy friends (Larouche & Chin-Peuckert, 2006).

Literature regarding self-perception in AYA in treatment for cancer is limited, but there is some evidence about self-perception in children with cancer. One study asking participants ages 7-12 to draw images of themselves during treatment for cancer revealed that pediatric cancer patients have weak self-perception, often portraying self-images reflective of their physical appearance differences and isolated status from others (Sadruddin & Hameed-ur-Rehman, 2013). This study reveals that even younger cancer patients' self-perception is affected by their cancer diagnosis and treatment. Among AYA with cancer, a group that is considerably more concerned with body image and connection to peers, it is curious how a cancer diagnosis further affects self-perception for this age group. Some evidence from studies examining self-perception in AYA cancer survivors is telling: Hörnquist et al. (2015) found that AYA cancer survivors have poorer self-perception when compared to the general population, particularly in areas regarding body image, sports/physical activities, peers, work, and global self-esteem. Females also had

poorer outcomes in self-perception for physical appearance, and the type of tumor and history of radiation treatment also predicted poorer self-perception in AYA cancer survivors (Hörnquist et al., 2015). Although conducted with AYA cancer survivors, this work shows that AYA with cancer are indeed at risk for negative self-perception into survivorship and suggests that psychosocial intervention promoting positive self-perception is needed throughout treatment (Hörnquist et al., 2015).

Given what is known about the importance of friendships, peers, physical appearance, and self-esteem for self-presentation among typically developing and AYA with chronic illness, the primary domains of self-perception which may associate with self-presentation online among AYA with cancer are social competence, global self-worth, close friendship, and physical appearance (see Figure 4).

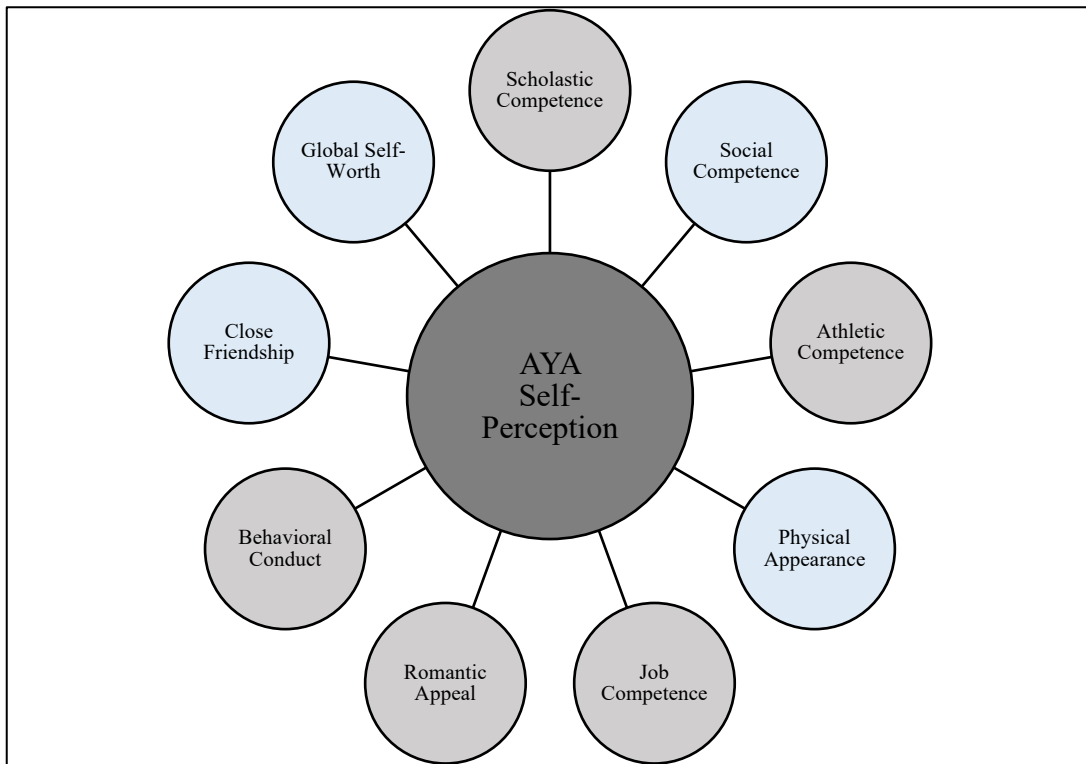


Figure 4. *Domains of AYA Self-Perception*

Connecting Self-Presentation and Self-Perception among AYA

Self-presentation is an activity that helps answer AYA identity questions (Calvin, 2020). AYA social media use is linked to both intrapersonal and interpersonal well-being, such that AYA social media informs self-esteem, body image, self-concept, and social support (Toma et al., 2020). Self-esteem, body image, and self-concept are all indicators of one's self-perception (Harter, 2012b). Thus, activities online which relate to these aspects of well-being connect self-presentation and self-perception. Profile construction and the receipt of feedback are two components of self-presentation, and these activities are positively related to AYA self-concept (Toma et al., 2020). However, social media activity among AYA is not always positive, and some online interaction leads to negative outcomes through social comparison or attempts to achieve self-concept clarity (Toma et al., 2020). As AYA engage in online activities that promote social acceptance, like using hashtags to symbolize a relationship with a social group, they look for feedback to indicate whether or not their self-presentation strategy was successful (Sriplo & Thomas, 2019). The responses from others in 'likes', comments, and followers then impact their self-esteem (Sriplo & Thomas, 2019).

Literature regarding online self-presentation related to aspects of the self often examine the ways in which people manage the impressions of others through specific online behaviors. Researchers who hold a traditional view on identity describe research questions investigating discrepancies in posting images that reflect the real or the ideal self. A study by Young (2013) examined the ways people manage their identities on Facebook through sharing status updates, posting photographs, and joining groups/pages (Young, 2013). Notably, the participants in her study described posting photographs about events as an important aspect of connecting the online and offline worlds. Indeed, when sharing images online, an individual may be communicating their perceived self-identity as well as their social identity (Michikyan et al.,

2015). For example, if someone posts an image that indicates their support of a sports team, they may be communicating with their online audience about their own interests as well as their sense of belongingness to a social community (Michikyan et al., 2015). In this way, the meaning of taking and sharing photographs online has evolved from an original purpose of documenting a moment and establishing future memories, to newer purposes of getting feedback from peers and demonstrating participation in social norms (Young, 2013).

Although this study was conducted with adults and on Facebook, the findings reveal how most often, users choose to share photos that look good, project a desired self-image, or represent an occasion (Young, 2013). Each of these themes may be relevant when thinking about the decisions that AYA make before sharing an image online. Indeed, AYA similarly report enjoying social media as a space where they can express their multi-faceted self, but they also feel obligated to themselves, to their relationships, and to social norms to present themselves in a way that is consistent with their offline selves (Davis, 2012). When describing the use of social media for expression, AYA report that it is important to share authentic expressions of the self. Some AYA even say that discrepancies between off- and online presentation of self can lead to a confusing internal sense of self (Davis, 2012). These studies begin to explore the relationship between online self-presentation and general sense of self-perception.

More important than the content of the presentation or motivation for the presentation given online, is the role of peer feedback on social media in shaping self-views among AYA. Feedback relates to AYA self-evaluations on- and offline. Whether an AYA receives or does not receive a 'like' is related to their self-acceptance (Cipolletta et al., 2020). One study revealed that 'likes' positively impact self-esteem, but a high amount of 'likes' also increases AYA dependence on social approval, and that dependence has a negative impact on self-esteem

(Meeus et al., 2019). This dynamic is interesting because it draws on the idea that the social/cultural meaning of the feedback is just as important for predicting outcomes in self-evaluation among AYA. In other words, the cultural meaning of likes is social approval, and the AYA orientation toward social approval means more for their self-esteem than the effect of the 'like' on their self-esteem in that one instance.

Jong and Drummond (2016) also examined the role of peer feedback in social media use with healthy AYA. They adopt a social constructionist framework, emphasizing the role of communication and shared meaning systems that construct and maintain social life (Berger & Luckmann, 1966). The authors were concerned with learning, from the AYA participant themselves, how social media experiences shape individual beliefs about their body image and their ideals- two important contributors to self-development. The findings from their study revealed that 'likes' are not always a message of approval on the image shared, but rather sharing 'likes' with peers is just a typical social activity for this age group (Jong & Drummond, 2016). In other words, trading 'likes' is simply a process of negotiating the maintained shared respect or positive evaluations between friends. Another interesting finding from their work is that adolescents seem to be aware that the practice of trading 'likes' is strange- when the researcher probed the AYA participant with questions about why they trade 'likes', the AYA participants reflect that it is a "stupid" social practice (Jong & Drummond, 2016). This finding supports the idea that, although adolescents and young adults do in fact have agency in the ways that they interact online, and they acknowledge that peer feedback is not always indicative of a sense of approval or evaluation, they may not be immediately aware of that understanding and engage in activities that are social norms without much explanation.

Another interesting finding connecting self-presentation and self-perception, is that self-presentation by AYA on social media may differ in times of transition or change. Life events that mark transitions in AYA life are associated with a need for AYA to reclaim or redefine themselves. For instance, in the transition from high school to college, AYA self-presentation online changes over time (Yang & Brown, 2016). When AYA are intentional about self-presentation online during these transitions, they engage in self-reflection which has been related to lower self-concept clarity in the moment, but higher self-esteem over time (Yang & Brown, 2016). This demonstrates how online self-presentation can encourage AYA consideration about the self, and while those AYA may lack clarity about the self in the moment, the intentional act of self-presentation has a positive impact on self-esteem, a factor of self-perception, later on.

Self-presentation on social media undoubtedly relates to ones' self-perception, but the literature examining this relationship among AYA with cancer is not direct. Communication about cancer, although not necessarily online, contributes to socialization but fear of poor reactions is a reason for not engaging in communication about cancer (Janin et al., 2018). Within online patient communities or illness blogs, self-presentation related to their illness experience serves as way to make meaning and to build self-esteem (Nesby & Salamonsen, 2016). Given what is known about self-presentation on social media and self-perception among healthy AYA, and what is known about disclosure offline or on illness specific online communities among AYA with cancer, this study proposes further consideration of AYA with cancer self-presentation on normative social media and how that relates to self-perception during treatment.

Important Topics for Self-Presentation and Self-Perception in AYA with Cancer

Although this review of the literature as primarily focused on the ways in which elements of self-presentation affect self-perception, it is important to consider that the relationship

between self-presentation and self-perception is not unidirectional. Strategies to control others' impressions of oneself may be utilized more often by users with a developing sense of self, whereas individuals with a stable sense of self have less motivation to alter their actions in order to manage others' impressions (Keep & Attrill-Smith, 2017). For AYA with cancer, self-development is disrupted and ongoing. Therefore, the relationship between self-presentation and self-perception, regardless of the direction, is of interest for this population.

Recall how Goffman's (1959) theory of self-presentation acknowledges the interplay between an individual's front stage performance and backstage performance in contributing to overall self-development (Goffman, 1959). When applied to the current study, online self-presentation can be understood as the front stage performance whereas several experiences related to a cancer diagnosis may primarily exist in the backstage interactions for an AYA with cancer. Understanding the relationship between self-presentation and self-perception among AYA with cancer requires thoughtful attention to the underlying concepts which are important in the AYA cancer experience. Social support, cancer impact, and coping are potential variables that link self-presentation and the developmental outcome of self-perception in AYA with cancer.

Social Support

Peers are important for all AYA, but particularly for AYA with cancer (Kaluarachchi et al., 2020). It is well-known that AYA with cancer suffer from social isolation during their cancer experience. AYA with cancer report a need for social support and find social support to be particularly important in terms of presence, distraction, maintaining autonomy, and communication (Pennant, 2019). AYA perceive a lack of support especially when friends are absent during treatment or when friends show a lack of understanding about appearance changes

that occur due to treatment (McDonnell et al., 2020). The ability to maintain friendships during treatment for cancer can ease the transition into survivorship, and social media one way for AYA to stay in touch with friends (Choquette et al., 2016; Daniels et al., 2021). But given that peer feedback online via ‘likes’ or comments indicates approval or support to AYA social media users, AYA with cancer may be particularly sensitive to the feedback they receive when posting about their cancer experience if they perceive a lack of understanding from friends given their response. Indeed, although social media may serve as a space for AYA to gather social support from peers, perceptions about the emotional safety and trustworthiness of an online community may predict whether or not social media is a place to receive social support (Gibson & Trnka, 2020).

Many papers evaluating how AYA with chronic illness perceive online social support propose the development of specific interventions or communities for support (i.e., Ahola Kohut et al., 2018; Iannarino et al., 2017), rather than explore a general sense of social support online. Although the literature on motivations for social media use within normative platforms among AYA patients themselves is limited, literature about caregivers of AYA cancer patients reveals some motivation for posting about cancer on Facebook. A study found that caregivers feel that posting about their young adult’s cancer online provides them with social support that they would not otherwise have received (Warner et al., 2020). They further state that it helps them feel less isolated because they can connect with others who relate to their experience. But these social support gains are not without some drawbacks. Caregivers of AYA with cancer report feeling like sometimes people responded to their posts in ways that made them feel *less* supported- like making light of their situation or commenting in a way that made the caregiver feel bad about sharing the post at all (Warner et al., 2020). The most important finding from this

study is that these consequences influenced whether and how the caregivers ultimately used social media throughout their child's treatment. When the caregivers faced negative consequences and feared judgement from their social media audience, they refrained from posting about cancer altogether (Warner et al., 2020).

Cancer Impact

Life events, such as a cancer diagnosis, can impact AYA identity achievement (McCullough et al., 2000; Watanabe, 2020). Specifically, negative life events are associated with weaker identity achievement among healthy AYA (Watanabe, 2020). While major life events relate to AYA self-concept, daily life events (both positive and negative) are just as meaningful for predicting AYA well-being outcomes (McCullough et al., 2000). Given that a cancer diagnosis is a major life event that also determines many daily activities (i.e., medication routine, daily treatments, changes in activities) the cancer experience may play a meaningful role in AYA self-presentation and self-perception. Even when cancer is not reported as a traumatic event among AYA cancer survivors, the cancer experience plays a central role in AYA cancer survivors' identity (Cook et al., 2020). For instance, one reason AYA cancer survivors choose to engage in self-presentation related to their illness via offline disclosure is because they report that cancer had a large impact on their life, and they want to include others in knowing about that experience (Barnett et al., 2014). In this way the perceived impact of cancer on one's life motivates self-presentation related to illness. However, when cancer has a significant impact on relationships, AYA with cancer may also need more guidance regarding how to engage in self-presentation related to their diagnosis. AYA with cancer report needing more assistance managing social relationships when they perceive that cancer has a large impact on those

relationships (Kent et al., 2013). Finally, youth with more cancer-related stressors report a lower self-perception (Hockenberry-Eaton et al., 1995).

Coping

Coping is a concept that can be defined in many ways, but for the purpose of the current study, coping is an indicator of the way an individual responds to stress. Social media use during treatment is related to coping among AYA with cancer as it provides distraction, information, and normalcy during treatment (Al-Omari et al., 2017; Iannarino et al., 2017; Kyngäs et al., 2000). Additionally, cancer-related disclosure to others can be helpful for coping with the experience (Janin et al., 2018). However, there are no studies which currently examine the two of these findings together on normative social media platforms used by AYA with cancer during treatment. However, self-presentation via sharing illness narratives in video format has been associated with coping via processing negative life events and enhancing meaning making (Pereira et al., 2019). Many AYA with cancer reported issues related to self-esteem in these video narratives, which demonstrates the usefulness of self-presentation as a means for processing self-perception during treatment (Pereira et al., 2019). Unfortunately, AYA also report feeling pressure to use social media in specific ways, like at a time of day where friends will see their content or by sharing content that they think will receive positive feedback from their online audience (Yau & Reich, 2019). Cancer treatments can contribute to disrupted routines and side effects which are undesirable to post or hinder the time of day that a patient can post. For instance, if a patient is in pain or is feeling self-conscious about their appearance, they may be less likely to post something online at that time (Daniels et al., 2021). In this way, a patient's response to cancer-related stressors like disrupted routines and altered physical appearance may impact their self-presentation and self-perception during treatment. Finally,

response to stress is related to the ways in which AYA with chronic illness evaluate themselves. Among AYA with HIV, perceived stress and coping style are both associated with self-concept, and reported self-concept is lower than compared to healthy AYA (Ke et al., 2020).

The Current Study

This study focuses on the social experiences of AYA with cancer and aims to understand their social media self-presentation and self-perception. Given the lack of literature surrounding AYA with cancer self-presentation on normative social media sites, this study first aims to collect qualitative data from AYA patients on treatment for cancer regarding those experiences. From the qualitative data, themes are evaluated that are unique to the cancer experiences of AYA that play a role in self-presentation, including cancer-related disclosure and peer feedback. Potential elements to consider as meaningful to AYA with cancer self-presentation and self-perception are the roles of social support, both off- and online, the role of coping, and the impact of cancer on the AYA. In the second phase of the study, there is a further investigation of the outcome of self-perception among AYA on treatment for a cancer diagnosis.

The current investigation is grounded by previous research, but no studies have connected self-presentation and self-perception together in this population. Some studies explore the role of self-presentation on social media in healthy AYA as a means for self-development (Vogel & Rose, 2016). These studies reveal the motivations of self-presentation to present a likeable image of the self and to receive positive peer feedback (Calvin, 2020; Metzler & Scheithauer, 2017). The literature concerning healthy AYA further supports the relationship between self-presentation and self-perception, such that types of self-presentation gain peer feedback which affect aspects of self-perception, such as self-esteem and global self-worth (Sriplo & Thomas, 2019; Toma et al., 2020). Although some research begins to explore the role

of self-presentation online among AYA with cancer (i.e., Marôpo & Jorge, 2017), many studies only evaluate the experiences of AYA cancer survivors or self-presentation on cancer-specific online communities (Keim-Malpass et al., 2016; Love et al., 2012; Suzuki & Beale 2006). On these platforms, the evidence suggests that cancer-related disclosure is useful for self-esteem, meaning-making, and social support among AYA cancer survivors. However, given that AYA are sensitive to healthy friends' perceptions of changed physical appearance during treatment, and that AYA with cancer report using the internet as a space for normalcy, more information regarding this relationship is needed to best support AYA as they endure the stressors of cancer.

Contemporary care for AYA with cancer requires providers to best understand the spaces where AYA most frequently engage with others. Some work begins to recommend that providers ask their patients about social media use (Gentile et al., 2018). These recommendations stem from the role of social media as potentially helpful for AYA with cancer to access social support and health information, but providers are also concerned that some information is not accurate and invasive of AYA patients' privacy (Gentile et al., 2018). The current study extends even further to suggest that providers inquire about AYA with cancer social experiences on their normative platforms. Interventions that promote socialization during treatment to support AYA with cancer can help predict long term outcomes of well-being (Docherty et al., 2015). For this reason, the current study explores concepts that will best inform the design of such interventions.

Given that few studies bring all of these concepts together, this study relies on the qualitative data to conceptualize which variables are relevant for further examination in relationship with self-perception- how they perceive themselves- however, literature suggests that potential illness variables related to the objective/subjective realities that knowledge of self-

perception include social support, cancer impact, and coping. As such, these are the research questions:

- (1) Qualitative: How do AYA with cancer describe their social interactions on social media since diagnosis?
- (2) Quantitative: What are the relationships among social support, cancer impact, and coping on self-perception in AYA with cancer?
- (3) Mixed Methods: How do stories from AYA with cancer about social interactions on social media inform our understanding of self-perceptions in many AYA with cancer?

CHAPTER 3

Methodology

This mixed methods study addresses a need to better understand AYA cancer patients' social media interactions and how those interactions are important for self-perception throughout cancer treatment and beyond. An exploratory sequential research design was applied to the study. In this type of design, qualitative data was collected and analyzed in an initial phase of the study and quantitative data collection and analysis followed in a second phase of the study. In the qualitative phase of this study, photo-elicited interviews were used to understand AYA experiences on social media since diagnosis. The results of the qualitative data contextualize social and illness variables important for self-perception in AYA with cancer. In the second phase of this study, instruments and questionnaires were used to quantitatively explore the relevance of the recognized variables on self-perception in a larger group of AYA treated for cancer. Cancer may impact AYA psychosocial development, but it is important to understand which variables promote healthy development so that interventions targeting these variables may be used to enhance healthy AYA development throughout treatment for cancer.

Studies framed in social-psychological lenses are the primary discipline using mixed methods research (Bryman, 2006). Importantly, mixed methods research does not mean that closed-ended questions are asked alongside open-ended questions in a single instrument (Bryman, 2006). Instead, mixed methods research thoughtfully combines qualitative research design and analysis with quantitative research design and analysis and results are integrated to understand the research problem (Bryman, 2006).

The main reason for using mixed methods in this study is *context*: Bryman (2006) writes that the rationale of *context*, “refers to cases in which the combination is rationalized in terms of

qualitative research providing contextual understanding coupled with... broad relationships among variables” (p. 106). An additional scheme of mixed methods research used in this study is *confirm and discover*, which “entails using qualitative data to generate hypotheses and using quantitative research to test them within a single project” (Bryman, 2006, p.106). These rationales help to clarify the grounds for using a mixed method design in this study and situate the aims of each arm of the research design.

Mixed method studies are used in both social media and in health care research (Regnault et al., 2018; Snelson, 2016). In social media mixed method research, the qualitative and quantitative phases of study often include collecting data with people and from social media content (Snelson, 2016). This approach values social media as a resource of insightful information that supplements data collected from people. This study similarly views social media as a resource for further understanding variables explained by people in interviews and questionnaires. In order to tap into this perspective, the qualitative phase uses photo-elicitation method to bring social media posts to the forefront of the interview experience. In the quantitative phase, questionnaires directly ask about participants’ social media habits and perceptions. In health care research, mixed method designs explore health outcomes in more comprehensive ways by addressing a research problem in an integrative perspective (Regnault et al., 2018). Importantly, mixed methods in health care research highlights the importance of small populations and gives insight to otherwise complex topics (Regnault et al., 2018).

Research Setting

This research study took place at a pediatric research hospital in the mid-south region of the United States. Interviews collected during the qualitative phase of the study occurred in a private space in the psychology clinic, medical clinics, or inpatient rooms. Questionnaires for the

quantitative component was administered on a tablet or on paper and AYA were given a choice to complete the questionnaires in a private space in the psychology clinic, medical clinics, or inpatient rooms.

Study Population

It is estimated that 89,500 AYA (15-39 years) were diagnosed with cancer in 2020 in the United States (American Cancer Society [ACS], 2020). 30,700 of those cases were diagnosed in persons ages 15-25 years (ACS, 2020). The research site treats pediatric and AYA patients, seeing around 7,500 patients each year. Many of these patients are on continuing treatment plans, but approximately 110 of new patients seen each year are 15 years or older. The participants for this study were patients ages 15-22 who are on active therapy for the qualitative arm; an AYA is ‘on therapy’ if they are 2-12 months from diagnosis and receiving cancer-directed therapy. For the quantitative arm, patients who are off therapy are also included (see further discussion in Chapter 4).

Study Sample

The participants in this study are a subsample of participants recruited for a larger ongoing study at the same institution. The qualitative portion of this study targeted 7-10 AYA participants and the quantitative portion of this study targeted up to 50 AYA participants. All participants must read and speak English. AYA from all diagnostic groups- brain tumor, solid tumor, leukemia/lymphoma- and developmental periods – high school, post-high school – were targeted, and thoughtful recruitment ensured that data were collected from a representative sample. Additional characteristics including gender identity, length of time since diagnosis, race, ethnicity, sexual orientation, relationship status, and preferred pronouns were tracked during data collection as an additional means to ensure representation from various groups. Participants were

ineligible for this study if they have an IQ less than 70 as documented in the medical record, a diagnosis of a genetic disorder, pre-existing condition associated with neurocognitive or social impairment, or an inability or unwillingness to provide written informed consent by the participant or legal guardian/representative.

Data Collection

Exploratory sequential design is appropriate for studies that have an inductive approach with plans to use themes that emerge from the qualitative analysis to inform the quantitative phase of data collection so that the inquiry is grounded in theory and in the perspectives of participants (Creswell & Plano Clark, 2018). There were two points of integration in the current study. First, building integration occurred at the methods level following qualitative analysis and prior to the quantitative phase of the study (Fetters et al., 2013). A building approach to integration is the process of using the data from one phase of the study to inform the data collection in the other phase of the study (Fetters et al., 2013). For this study, the building integration occurred following the qualitative analysis, in which concepts that emerged from the thematic analysis were used to inform variable selection for data analysis in the quantitative phase of this study.

Final integration occurred after both sets of qualitative and quantitative data were analyzed, results were connected, and interpretations were applied to the qualitative results (Creswell & Plano Clark, 2018). The final integration occurred through the process of creating side-by-side joint displays comparing results from both interview and questionnaire data. Following this process, the quantitative findings provided new insights regarding the research questions. See Figure 5 for a visual representation of the steps of this exploratory sequential

mixed methods study, including both integration processes (Creswell, 2013).

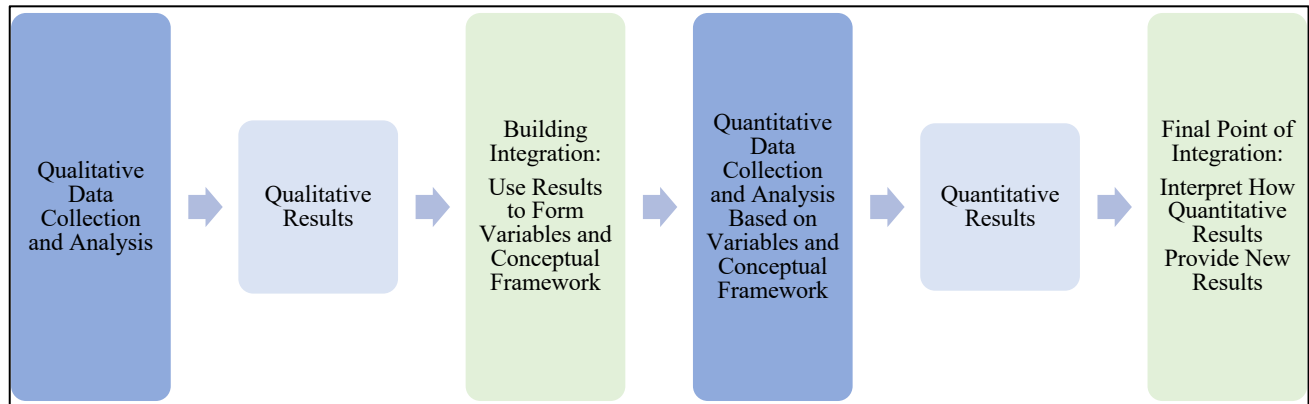


Figure 5. *Exploratory Sequential Mixed Method Research Design*

Several diagrams for exploratory sequential mixed method designs include a phase of instrument development. Indeed, one way to execute this research design is to use qualitative data to develop a quantitative measure and then to test that measure (Creswell & Plano Clark, 2018). However, Creswell and Plano Clark (2018) also describe a connection between qualitative and quantitative phases as identifying variables to be tested that help expand the problem. This has been done in research on difficult topics, and specifically on research with adolescents. For example, a study evaluating mental health in homeless adolescents used an exploratory sequential design to explore the complexity of the situation, using the qualitative data to frame the views that homeless youth have on health and wellbeing and then testing the determinants and extent of those views in a quantitative analysis (Oppong Asante et al., 2016). This study used a similar approach; because little is known about the specific variables that contribute to self-perception in AYA with cancer, the qualitative data helped to build variables and frame their relationship to self-perception from the perspectives of AYA themselves. These variables were then be explored quantitatively.

Qualitative Component

The first phase of this study is qualitative. Qualitatively driven studies are often concerned with context (Mason, 2006). In order to understand a phenomenon, that phenomenon must be contextualized, and dynamics of the setting and the individual must be understood. When approaching a mixed method design from a qualitative perspective, researchers are first enhancing their understanding about variables experienced within a specific context so that they may be able to consider how these variables are applied in larger contexts (Mason, 2006). In this way, context transforms into explanation of how variables are associated with one another (Mason, 2006). When studying AYA with cancer, qualitative mixed methods studies offer a comprehensive structure to understanding the unique preferences and experiences of this population. This design lends itself as justification for introducing new interventions that support age-appropriate care (Lea et al., 2018).

Methodology. The methodology that was used for the qualitative portion of this study is narrative inquiry. Recall that the macro theory for this study is social constructionism, which promotes knowledge acquisition through social interaction and through reflective processing through language and dialogue (Berger & Luckmann, 1966). The qualitative component of this study adhered to this understanding through the use of narrative inquiry as the methodology. Narrative inquiry is a methodology for studying lived experience, and it is commonly used in education, social, and nursing research (Clandinin et al., 2007). Clandinin (2006) describes narrative inquiry as a relevant methodology for studying lived experience, because people create meaning through the stories they create and share with others. There is an understanding that stories and the meanings gleaned from stories are dynamic. Each story is shared within the dimensions of temporality, sociality, and place (Clandinin & Huber, 2010). This means that shared stories are not permanent, but flexible and ever-changing; a story cannot be understood

without consideration of the personal qualities and values of the narrator and the listener, and all stories are contextualized under the social and physical conditions that they are shared within (Clandinin & Huber, 2010). Narrative inquiry, then, does not place expectations of an answer to be discovered through story telling. Instead, narrative inquiry invites continuous exploration into understanding experience (Clandinin & Huber, 2010). Stories continue to evolve even after they are shared, as they are thought about in new spaces, new phases of life, and with new listeners, the narratives are seen as always incomplete or in progress. The meanings from narrative inquiry are not certainties about human experience, but rather descriptions of the possibilities of what might be (Clandinin & Huber, 2010). A researcher concerned with proclaiming facts following their research would not be suited to use narrative inquiry. Instead, researchers engaging in narrative inquiry must be open to the stories that are shared with them and listen closely to the words, contexts, and persons involved in these lived experiences.

As a narrative inquirer in this study, I asked AYA to share their diagnosis story and their experiences on social media throughout their treatment. Social media is a platform for storytelling, thus appropriately providing context for narrative inquiry as a methodology that understands the individual and social nature of storytelling to interpret meaning (Clandinin, 2006). Through interactive storytelling on social media, people can make sense of themselves and their experiences (Page, 2013). I remained open to hearing the stories as they are shared by the participants and acknowledge my own interaction through dialogue with participants as a psychosocial provider. Clandinin & Huber (2010) recommend justifying use of narrative inquiry using personal, practical and social justifications. My personal justification for using narrative inquiry is that my own lived experience as a child life specialist has provided me with complex and meaningful understandings of the lives of AYA with cancer (as demonstrated in the story

shared at the beginning of this dissertation). As I reflect on my own story as a psychosocial provider and advocate for AYA with cancer, I remember how powerful it felt the first time I asked someone to share their diagnosis story with me. While so many people ask AYA why they are at the hospital or what their diagnosis is called, I asked them to share their memories from the day they were diagnosed, their impressions of what that means for their life now, and what they will choose to disclose with peers. The privacy and space to discuss these topics away from peers, parents, and other providers acted as a safe venue for processing the meaning of this new experience, cancer, that they now have to endure.

My practical justifications for using narrative inquiry also stem from my experiences in conversations with patients. While child life specialists working with much younger children use play to assess their patients' coping and adjustment, I work solely with AYA and have a different privilege of building rapport through storytelling and dialogue. Each conversation with an AYA shows me that no two experiences are alike. Their stories help inform my practice and what interventions I use to support them while they are at the hospital. Rather than assume there is one shared experience of AYA with cancer, I am able to consider the unique differences of each experience and seek to understand those through conversation. I feel confident that the only way to make changes to improve AYA support and development in the hospital setting across disciplines is by deepening the general understanding of AYA experience through attention to narratives of their experiences.

The social justifications for using narrative inquiry for this study are both theoretical and socially active. Using narrative inquiry to explore AYA social interactions on social media throughout cancer treatment contributes to disciplinary knowledge in psychosocial and developmental disciplines. While several narrative studies examine the context of social media

for AYA identity development or the impact of cancer for identity development in AYA, the two contexts have not yet been explored together (Pearce et al., 2020; Spies-Shapiro & Margolin, 2014). Narrative inquiry is the most appropriate methodology to expand this research, because it recognizes that one's identity is a part of their experiences and the sociocultural settings of those experiences (Clandinin, 2006). Additionally, using narrative inquiry to learn about AYA experiences with cancer may provide methodological knowledge by demonstrating its use as a valuable and age-appropriate research method in the hospital setting. Finally, the social action justification for using narrative inquiry is through its ability to give AYA control over the stories that are shared. Peers and parents often share stories of their friend's or child's cancer diagnosis as part of their own story. With AYAs already having limited control in the hospital, it is important to find opportunities for them to exercise control. Narrative inquiry provides AYA with freedom to selectively share the stories from their perspectives.

Method. The method for data collection for the qualitative portion of the study was semi-structured interview, with photo-elicited questions. The purpose of the interview was to elicit narratives from AYA about their social experiences throughout treatment for cancer, and to ask more specific questions about their social media preferences, posting habits, and perceptions of feedback.

Photo elicitation is a unique method of interviewing because it provides a different level of engagement between the interviewer and the interviewee. First, using photos during interviews enhances the visual-verbal relationship, especially when those photos are personal to the participant (Harper, 2002; Tinkler, 2014). When the participant has an emotional connection to the photo being discussed, it can enact a memory response where they recall the story behind the photo (Tinkler, 2014). Similar to narrative inquiry, photo elicitation encourages reflective

meaning making that is contextualized in temporal and social spaces (Tinkler, 2014). For instance, when people share about a photo, the context is not only about the time the photo was taken, but also the time that the person is recalling that experience, during the interview. In this study, the additional context of social media platform is another point of temporal interest- the time that they decide to share photos with others. Tinkler (2014) describes an important practice for researchers to adopt during photo-elicited interviewing as listening to a ‘layering of memories.’ Because there may be several emotions and memories surrounding a single photo, it can be hard for the participant to focus on a given question. Patience and attentive listening provided meaningful conversation that evoked narrative from the participant (Harper, 2002).

From a social constructionist perspective, knowledge of AYA self-presentation on social media could not be understood by observation of social media interactions. Instead, social interaction and exchanging dialogue to co-construct an understanding is important, especially when surrounding photographs. The meanings of photographs are subjective and shared meanings can only fully be understood through discussion of those images between people (Leonard & McKnight, 2015; Richard & Lahman, 2015). In addition to photographs being a resource for researcher to connect with participant and to enhance shared understanding, photo elicitation also allows for new insights of the research topic to arise which may not have been present if only standard interview were used (Leonard & McKnight, 2015). Dialogue combined with a visual facet of the discussion enhances the interpersonal exchange of meaning.

Photo-elicited interview does not always produce desirable results. Some researchers found difficulty engaging participants in photo-elicited interviews when the topic of the photo was something very emotional to the participant or when the photo brought up a subject that the participant had not yet worked through (Tinkler, 2014). Narrative inquiry encourages

consideration of all interpersonal and sociocultural factors that contextualize a narrative, and it was important to keep the context of illness at the forefront of my understanding should interviews become sensitive or challenging. While cancer is something that I, as a provider, see every day, it is only one part of my world. For patients and families, cancer is pervasive, inescapable, and disruptive to their typical routine. From a developmental perspective, discussing a photo that represents an image of the self while undergoing treatment for cancer may be challenging for patients struggling to adjust to these changes. For this reason, participants were told ahead of time that the interview would include a portion asking them to share a photo from social media that they have posted since diagnosis that stands out to them. This provides freedom for the participant to select an image that they are comfortable discussing, and it may or may not be hospital or illness specific.

Photo elicitation is useful when studying self-development in AYA with cancer. Studies that use photo elicitation with AYA aged participants find it to be a desirable method for connecting with this age group and for enhancing the perspectives shared in interview (Croghan et al., 2008; Hanghøj et al., 2016).

Procedures. The interviews collected for this dissertation study were drawn from a larger ongoing study. The first 8 interviews that I conducted as a part of this larger study were used for this dissertation research. AYA who met the inclusion criteria were approached by trained clinical research associates in the medical clinics or were mailed an introductory letter with a follow-up phone call. Written informed consent was obtained. AYA who agreed to participate in the qualitative component of the study were then scheduled for a time to participate in a semi-structured interview with a trained researcher. Participants received a \$10 gift card for participating in the interview. AYA were instructed to bring a photo with them that they have

posted on social media since diagnosis. Interviews were around 30-60 minutes and were audio recorded. The researcher jotted notes regarding observed behaviors that could not be captured on the audio recording on the interview guide. All recordings were immediately uploaded to a folder on a secure drive shared by the research team. Interviews were transcribed verbatim. Transcripts were de-identified and stored in a different folder on the secure shared drive.

Instrumentation. The research team for this study collaborated to create a 14-question semi-structured interview guide with probes. The initial questions open the illness narrative by asking the AYA to share their diagnosis story. Questions build to discuss friendships throughout cancer treatment and a photo-elicited question is used to explore AYA social media use and peer relationships. The interview guide is included in Appendix A.

Quantitative Component

The aim of the quantitative phase of this study was to refine the conceptual framework connecting social media interactions and self-perception in AYA with cancer based on the variables discussed in the qualitative phase. As Harter (2012b) describes, self-perception is a complex feature of self-development but is an important variable associated with self-esteem, global self-worth, and other self-evaluative processes important for healthy development. When studying self-perception in complex populations, such as AYA with cancer, it is important that assessment of self-perception does not follow a single assessment procedure (Harter, 2012b). Doing so undoubtedly ignores a variety of dynamic social and interpersonal factors that play a role. In previous work studying self-perception in populations of youth with medical conditions, the role of social media was not directly explored. By connecting data from the qualitative phase of this study with a quantitative exploration of variables that are important for self-perception in

AYA with cancer, researchers and health care providers may design interventions that support aspects of AYA social life and sustain healthy development throughout treatment.

Design. The quantitative component of the current study was a non-experimental, descriptive research design using survey research. Survey research collects data from a sample of participants using questionnaires (Creswell, & Creswell, 2018). Questionnaires are instruments with closed-ended questions that obtain numerical data reflecting participant's opinions, attitudes, and orientations to the topic being evaluated (Creswell & Creswell, 2018). The current study included six questionnaires which serve as metrics for gathering information about social support, cancer impact, coping, and self-perception from a sample of AYA patients.

Procedures. Quantitative data on demographic and medical information, social support, cancer impact, coping, and self-perception were pulled from a larger ongoing study of AYA social experiences. Responses to these measures were collected from a group of 12 AYA participants who were treated for cancer at a research hospital in the mid-south of the United States. AYA were approached by a research team and were given the option to complete assessments in electronic or paper formats. The data from these responses were stored in a secure server only accessible to the research team. This study selected data from the relevant measures below. Data were collected and cleaned by the researcher. For further information on the treatment and analysis of data, see Chapter 4.

Measures. The following measures were used to assess demographic and medical information as well as to assess the social and illness variables associated with self-perception. The below measures are included in Appendices B-H.

Demographic and Medical Information. Demographic and medical information including sex, age, hometown, diagnosis, date of diagnosis, treatment plan, and established providers were obtained from the institution's electronic medical record.

Social Support. Two instruments were used to assess different aspects of social support. The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988) is a self-report questionnaire with 12 items assessing participant perceptions of support received from friends, family, and significant other. Each question is rated on a 7-item Likert scale with 1 = *very strongly disagree* to 7 = *very strongly agree*. Higher scores indicate more perceived social support. Three subscale constructs have been validated and are representative of sources of support. This measure is located in Appendix B.

The Online Social Support Scale (OSSS) (Nick et al., 2018) is a two-part questionnaire assessing the roles of online apps or websites in perceived support from others. First, participants respond to items regarding how frequently they use online platforms, such as Instagram or Facebook, to interact with others. The questionnaire includes free text boxes for participants to self-report unnamed platforms. Second, participants respond to 40 items that assess the types of esteem/emotional support, social companionship, informational support, and instrumental support that participants receive on these platforms. This measure was modified for the current study to include contemporary platforms for AYA online interaction. For instance, the original measure included Vine and Yik Yak, two platforms that no longer exist and were thus removed. Additionally, due to the primary focus of the current study regarding AYA interaction on social media sites rather than on chat services, some apps were collapsed into one category. For example, instead of listing "WhatsApp" on its own, this app was combined as an example along with "GroupMe" within the option "Chat Services." This measure is located in Appendix C.

Cancer Impact. Two measures were used to assess different aspects of cancer impact. The Young Adult Cancer Impact Scale (YACIS) (Schwartz & Drotar, 2004) is a self-report measure containing 5 items that assess perceived impact of cancer on education, social interaction, career goals, romantic relationships, and independent living. Each item is responded to on a scale from 1-10 with *1 = did not interfere/affect* to *10 = extremely interfered/affected*. Particular interest in this study regards the social interaction item. This measure is located in Appendix D.

The Centrality of Events (CES) (Berntsen & Rubin, 2006) is a self-report measure with 20 items assessing perceived impact of a traumatic or significant event on identity development. For the purpose of this study, participants are instructed to respond to the items while considering their experiences with cancer. The CES is reliable, with Cronbach's alpha reported at .94 and .88 in a large sample of undergraduates (Berntsen & Rubin, 2006). Additionally, the scale correlates with measures of PTSD, stressful memory, and depression demonstrating construct validity (Berntsen & Rubin, 2006; Gehrt et al., 2018). This measure is located in Appendix E.

Coping. The Responses to Stress Questionnaire- PC (RSQ-PC) (Compas et al., 2014; Connor-Smith et al., 2000) is a self-report questionnaire with 57 items assessing individual stress and coping. Participants are first asked to reply to a 12-item checklist rating the frequency that they have experienced specific stressors related to cancer (e.g. missing school, changes in personal appearance) on a 4-point Likert scale from *1 = not at all* to *4 = very*. They then respond to 57 items assessing voluntary (coping) and involuntary (autonomic) stress responses on a 4-point Likert scale ranging from *1 = not at all* to *4 = a lot*. Free text boxes are often included to gather more information on how certain strategies were exercised by participants.

Three forms of coping strategies- primary control engagement coping, secondary control engagement coping, and disengagement coping- as well as two types of involuntary stress responses- involuntary engagement and involuntary disengagement- are measured in the RSQ-PC. Reliability for the RSQ-PC has been demonstrated through reported internal consistencies ranging from .81-.84. Confirmatory factor structure analyses have also supported the use of the RSQ-PC among different groups of children and adolescents (Compas et al., 2014; Connor-Smith et al., 2000).

Although noted as an interesting concept to consider from the literature review, coping was revealed to be irrelevant to explore further in the current study. This decision is discussed in Chapter 4 and is a result of the building integration that occurred between the qualitative and quantitative phases of the study. To review the RSQ measure in its entirety, please visit the stress and coping research lab webpage included in the references to this manuscript (Stress and Coping Research Lab, 2021).

Self-Perception. Harter (2012a, 2016) developed the Self-Perception Profiles for Adolescents and for Emerging Adults (SPPA/EA) as a self-report measure of self-perception. For adolescents, constructs of scholastic competence, social competence, athletic competence, physical appearance, job competence, romantic appeal, behavioral conduct, close friendship, and global self-worth are assessed with this study having particular interest in social competence, physical appearance, close friendship and global self-worth. For emerging adults, constructs of intelligence, job/occupational competence, athletic/physical competence, physical appearance, peer friendships/social acceptance, intimate relationships, relationships with parents, morality, sense of humor, daily life management, optimism, true/false self-behavior, and global self-esteem are assessed with this study having particular interest in physical appearance, peer

friendships/social acceptance, and global self-esteem. The questionnaire contains 45 questions within the 9 subscales that provide alternative statements, such as ‘some teenagers [young adults] do very well at their classwork BUT other teenagers [young adults] don’t do very well at their classwork.’

The adolescent or young adult is instructed to consider which statement is more like them and to check either ‘really true for me’ or ‘sort of true for me’ next to their selected choice (Harter, 2012a). Items are scored on a scale of 4, 3, 2, or 1, with 4 representing most adequate self-judgement and 1 representing least adequate self-judgment (Harter, 2012a). Means can be calculated from each subscale to give an overall picture of self-perception in each construct. Internal consistency reliabilities for each subscale are reported ranging from .74-.93 (Harter, 2012a). Test-retest reliability is not reported because self-perception is dynamic and changes overtime.

The instrument demonstrates strong psychometric properties of reliability and validity. Harter (2012a) also acknowledges the challenges in assessing validity in a measurement of self-perception but reports convergent validity with subscale correlates to Marsh’s (1988, 1990, 1991) self-description questionnaires all reaching a .56 or higher correlation (Harter, 2012a). Additionally, Harter and colleagues have demonstrated discriminant validity for subscales of the self-perception profile across different groups of adolescents, and construct validity demonstrating the measures adequate assessment of the self for different predictors according to self-theorists James (1892) and Cooley (1902) (as cited in Harter, 2012a). These measures are located in Appendices F and G.

CHAPTER 4

Analysis and Results

This chapter presents the results of this study in three sections, (I) qualitative findings, (II) quantitative findings, and (III) integrated findings from mixed methods. The qualitative findings represent AYAs' stories about social interaction on social media since diagnosis. Following the report of qualitative results, the first point of integration occurred through a building approach, in which the qualitative findings informed the selection of relevant quantitative variables to explore in the next phase of the study. The quantitative findings describe which social and illness variables are important for self-perception among AYA with cancer. The mixed methods findings integrate these two concepts and represent how social experiences among AYA with cancer link to their self-development, particularly their self-perception.

Qualitative Results

The aim of the qualitative phase of this study was to learn how AYA with cancer describe their social interactions on social media since diagnosis. Given the social constructionist theoretical lens underpinning the approach to this study, knowledge acquisition was a collaborative and inductive process from the development of the interview guide throughout the process of interviewing participants using a photo-elicited question, and during transcript analysis and interpretation of themes. As noted in Chapter 3, data collection and analysis were guided by a narrative inquiry methodology. Meaning, the intent of gathering these stories was not to find an answer to a specific question about AYA social experiences, but rather to characterize AYA social interaction on social media through their stories.

AYA were encouraged to share stories about their experiences rather than to simply answer questions asked during the interview. This process encouraged AYA to also reflect on the

meaning of their experiences, and these perspectives offered insights to the important aspects of interactions that leave lasting impressions on the ways AYA consider their social media experiences since diagnosis. It is important to acknowledge that each story shared by AYA throughout data collection for this study stands on its own. Each AYA undoubtedly has past experiences and individual factors that shape their responses. However, through dialogue between the researcher and the participant, a deeper understanding of how to relate stories to one another. The themes thus represent a constructed understanding of how several AYA experiences characterize social interaction on social media since diagnosis.

The themes summarize important aspects of social interaction. The first theme regards how and where AYA engage in social interaction online. Specifically, the first theme describes AYA platform preferences and engagement habits (i.e., directly communicating with peers, creating content, and observing content created by others). The second theme shares how treatment impacts the ways AYA interact on social media, specifically describing how certain social and physical changes that occur during treatment affect the interaction with others online. The third theme captures how AYA consider the outcomes or potential outcomes of social interaction when posting about their diagnosis online. Lastly, the fourth theme addresses how interacting with others through sharing or seeing cancer-related content associates with social support in complex, yet meaningful ways.

The remaining section of this chapter provides a description of the participants and data collection methods, as well as the process for data analysis and a summary of the findings. Following the summary of findings, a building integration reports how the qualitative results informed quantitative variable selection for the next phase of the study. Examining the implications and drawing conclusions comes later, in Chapter 5.

Participants and Data Collection

Participants for this study were eight AYA with cancer, ages 15-21 years (63% male; 50% white). AYA were diagnosed with cancer between 4-12 months at time of interview (see Table 1). Participants were offered a variety of formats for completing the interview, including in-person ($N = 5$), video call ($N = 1$), or phone call ($N = 2$). Average length of the interview was 36 minutes.

Table 1

Demographic and Diagnostic Information of Interview Participants

Sex	Age	Race/Ethnicity	Diagnosis Category	Preferred Social Media Platforms	Months since Diagnosis
Female	16	White, Non-Hispanic	Solid Tumor	Instagram, TikTok, Snapchat	4
Male	16	Black, Non-Hispanic	Leukemia	TikTok, Snapchat, Instagram	12
Male	18	Black, Non-Hispanic	Leukemia	Facebook, Snapchat	12
Male	21	Asian, Non-Hispanic	Leukemia	Twitter, Snapchat, Reddit	6
Male	16	White, South/Central American	Leukemia	Snapchat, Video Games	5
Female	15	White, Non-Hispanic	Solid Tumor	Instagram, TikTok	3
Male	18	White, Non-Hispanic	Leukemia	Facebook, Snapchat	3
Female	15	Multiple (NOS), Non-Hispanic	Brain Tumor	Instagram, Snapchat, TikTok	5

Data Analysis

The analytic process for this phase of the study was thematic analysis. Following recommended steps by Braun and Clark (2006), interviews were first transcribed verbatim. The transcription process contributed to familiarity with the data. Notes were made during transcription to identify sections relevant to the research question. After transcripts were completed, each was read with the intent of inductively reviewing topics, noting ideas of concepts and phrases shared by participants that related to the study aim.

I began the coding process by independently performing initial coding of one transcript. A committee member coded the same transcript, and we discussed consensus on coding to ensure continuity in constructed understanding of the stories shared. This work assured rigor in the analytic process. I then coded the remaining transcripts independently. After all transcripts were coded in the initial cycle with open coding, a second cycle of focused coding occurred, where similarly coded content was reorganized into meaning categories. Example quotes for each meaning category were identified. Finally, categories were shaped into themes that represented important concepts from the dataset. Transcripts were re-read several times as quotes were selected that represented each theme. Once themes were finalized and quotes were selected, transitions were written in ways that related examples to one another to tell the story as it corresponded to the original research question.

Results

Thematic analysis of the stories shared by AYA with cancer revealed four themes about social interaction on social media since diagnosis: (1) enacting active and passive engagement depending on the platform, (2) changing habits due to aspects of treatment, (3) evaluating and

protecting self-image, privacy, and time (4) accessing and interpreting the meaning of social support.

Theme 1: AYA enact active and passive engagement depending on the social media platform. AYA use several social media platforms during treatment including Snapchat, Instagram, Facebook, and TikTok. Each platform offers AYA unique features for engagement and access to different social networks. Whereas some platforms promote connection with friends via direct communication, others are more useful for media consumption and entertainment. One participant summarized these differences across three platforms:

TikTok I just use for entertainment, 'cuz they have, like, a lot of funny videos and stuff like that on there. Um... Snapchat is used to, like, stay in touch with my friends and, uh, stuff like that... and then Instagram I just use to, like, like almost like the news, almost like the news, basically, just far as like what's goin' on and not like news news, but as far as what's goin' on in the social world, I guess you could say. (Male, 16, Leukemia-1)

The examples he shared were echoed by other participants. Consistently, Snapchat was referred to as the platform where AYA can interact with their friends online just as if they were hanging out in an offline space:

A lot of the times on Snap it's like we're not even really talkin' bout anything, we're jus' sending pictures back 'n forth, and then, like, I'll literally just take a picture, like, right here (referring to hospital bed) and send it to somebody who sent me a picture, and then they'll send me a random picture of, like, their ceilings, and I'll send a picture of the ground. It's not like we're actually always havin' a conversation it's just... ya know... I guess it's to kinda see- look and see what all they're doin'... 'n... ya know, sometimes

they're at the beach, er if they're at a certain place eatin' or hangin' out they'll send me a pic. (Male, 18, Leukemia-2)

Alternatively, TikTok was most often reported to be a place for AYA to access entertainment and to pass the time. Although the Snapchat platform includes access to pop culture entertainment, AYA only describe its usefulness as it relates to their offline peer network. Otherwise, they seek out TikTok. One AYA confirms this by saying:

I used to use Snapchat, but I don't really talk to anybody anymore [...] I like TikTok but I- I- I use it for more of informa- um, not information... but more for like entertainment than, um, anything else. I'm not connected to anybody that I know on there. (Female, 15, Brain Tumor)

Indeed, the social network on TikTok extends beyond close friends. Only one AYA said she created videos on TikTok, and another AYA said if his friends did create content on TikTok they would need to share that content on a different platform in order for it to be seen by friends:

A lot of [friends] don't really have accounts [on TikTok]- they don't, like, when they do post it, they don't post it on their TikTok, they'll, like, post it on their Snapchat or Facebook. (Male, 18, Leukemia-1)

Instagram is one platform where AYA merge active social interaction with friends and passive observation of content. Unlike on TikTok where AYA are mostly entertained independently, or on Snapchat where AYA are mostly messaging with others, on Instagram, AYA will observe content and then share about that content with their friends all within the same platform:

We share pictures with each other, mostly find funny stuff [...] It's just easier to share on, like, something we found funny on the group chat inside Instagram than it is to process it through our [text] message. (Female, 15, Solid Tumor)

Interestingly, all AYA share an understanding about how each platform is used in terms of the different types of interactions and networks. Some platforms are used to passively engage with content created by a broader social network while others are important for actively engaging with their inner circle of friends. This understanding allows AYA flexibility in selecting which platforms they are interested in using during treatment. While some AYA may engage in all platforms, others may prefer to only engage in one type of social interaction.

Theme 2: AYAs' social media habits change due to treatment experiences. AYA reported changes in their typical social media habits due to their treatment experiences. The two key habits that changed were the frequency of social media use and the type of social media engagement. AYA acknowledged both physical and social impacts of treatment when describing the reasons for these changes. For example, one AYA shared about how social and physical aspects of treatment affected her frequency of contact with friends:

We've gotten really distant, like, we don't talk as much anymore but hopefully that'll get better when we get back... cuz they're like my best friends [...] we used to [...] FaceTime a good bit [but] sometimes I don't really feel good. (Female, 16, Solid Tumor)

Even though negative side effects from treatment created challenges for keeping frequent contact, she shared that her favorite thing about social media was being able to connect with friends. But connecting with friends was not the only benefit AYA found in social media during

treatment. In fact, one AYA said her favorite thing about social media was not the ability to connect with friends, but rather that it provided entertainment:

I can spend hours on there and not get bored... and let's see- during treatment I just spend hours laying there. (Female, 15, Solid Tumor)

Another AYA also found that, after diagnosis, she engaged on social media more for entertainment than for social connection with friends. She describes how physical distance from friends impacted the way she used social media during treatment:

I haven't shared anything. I kind of just, like, stopped doing social media and stuff like that. I still use it, like, scroll through feeds and stuff like that and 'like' posts on, like, Instagram, but I don't post anything, not on my story, not on my feed [...] I think I was more, like, interactive [before diagnosis], so there was more, like, a lot more happening beforehand as well, and just, like, being at school as well, so that's a big thing for it- like, I know people on there are following me [...] but um.... like, just there's no use for me, I'm not interacting with those people and, like, they're not really interacting with me, why would I post something? (Female, 15, Brain Tumor)

Her perspective reveals that, when treatment plans alter offline social interaction, it can also change social media engagement habits. A different AYA agreed that treatment creates separation from typical spaces where social interaction occurs.

Since this [diagnosis] has happened, it [social media use] definitely has gotten a lot more... because I'm not home to be in. Like normally I- if I was at home, ya know, I'd be there, like, ya know... in person... uh, doing things... I wouldn't need social media as

much as I do ta stay in the know or know what's going on. I would just be able to... do it, you know what I'm sayin'?" (Male, 18, Leukemia-2)

During treatment, he altered his social media use to address separation through more frequent engagement. At times, the way treatment impacted social media engagement was less explicit. In addition to impacts in frequency and type of engagement, treatment also impacted the content that AYA shared.

Two AYA shared about posts they made since diagnosis, and both referenced treatment impacts in their captions. One AYA captioned a series of posted images saying, “*can't wait to be back*” referencing her anticipation to return home after receiving treatment. Another AYA reflected on a similar post he shared during treatment:

It's a black screen and then the words on it say, "patience is a virtue" [...] I was just thinkin' about everything that was goin' on at the time, like as far as me havin' the diagnosis and wantin' to get back home... and as far as COVID- waiting for COVID to pass or something like that... [...] so that, that's really where it came from. (Male, 16, Leukemia-1)

Even if AYA did not explicitly post about the hospital by sharing an image of their treatment experience, the posts they did share during treatment often referred to aspects of the cancer experience. Treatment impacted AYA social media in several different ways. Not all AYA saw similar changes, but every AYA felt some difference in the ways that they used and engaged in social media since diagnosis.

Theme 3: AYAs evaluate and protect their self-image, privacy, and time. When describing their decision to (or not to) post about cancer experiences on social media, all AYA

considered their offline circumstances and anticipated outcomes. While some AYAs experienced or feared others' judgements, more AYAs expressed concerns for privacy and for having limited time to address others' responses.

Feeling self-conscious was one reason preventing AYA from posting about cancer on social media. One AYA's self-consciousness even led him to deleting his social media platforms entirely:

After telling my closest friends I kind of deleted all of my socials and... I only, and like I kept the communication even to my friends at a minimum [...] because... uh, I just felt I had to go- I don't know, I wasn't really interested in like talking to anyone else. I guess it was like a ego thing? Like, people seeing me in a vulnerable position. (Male, 21, Leukemia)

Although he never positioned himself to receive feedback in this vulnerable time, his concerns are not unfounded. One AYA shared about the sole time she posted about her cancer experience and the outcome of that:

Only thing that I posted was shaving my head on there [...] and then, like, it was like one guy who, like, had a rude remark [...] it wasn't very nice (Female, 15, Brain Tumor)

Since then, she says she stopped posting on social media. Other AYA acknowledged the importance of privacy. In particular, one AYA had concerns that people would treat him differently if he disclosed about cancer. He made an effort only to post lighthearted content so that people would not find opportunities to pry for information about his diagnosis and treatment:

I don't wanna post nothin' sad or something like that and then people start asking me questions and stuff like that... which is why I didn't post nothin' about me havin' cancer,

cuz I didn't want people slidin' up and asking questions and all that type of stuff (Male, 16, Leukemia-1)

In addition to privacy, protecting time was another factor underlying AYAs' decisions to post about cancer. One AYA simply found a lack of time to make posts about his hospital experiences:

I'm busy... because it's like sometimes I'm gettin' labs, or something drawn so I can't really be fenagling with my phone. (Male, 16, Leukemia-2)

But other AYA were more intentional about their decision to protect time. Specifically, it deterred some AYA from making posts when they considered the effort it would take to respond to others' responses:

It's a lot of work for me. If people comment on said things... then, I have to answer those questions and that's a hassle. I don't wanna deal with that. (Female, 15, Solid Tumor)

While considering others' responses was only hypothetical for AYAs who decided not to post about cancer, an AYA who did post about his experiences confirmed the emotional effort and guilt to follow up with those who interact with cancer-related posts:

I don't ever think I had, well, hesitation or anything, like, I've never been one ta, like, hide and still to this day I'll tell anybody anything but, like, it's just... it's a lot of work to type it all out and have all these people comment on it and me thank em, you know... and make sure they all get thanked cuz I feel bad if I don't thank em or whatever. (Male, 18, Leukemia-2)

Sometimes AYA were hesitant to post about cancer because they anticipated negative outcomes. Other times AYA actually experienced those judgments and burdens. Whether perceived or realized, reasons that AYA choose to monitor their cancer-related content on social media are valid.

Theme 4: AYA access and interpret the meaning of social support that they receive online. When AYA shared content related to their cancer experiences on social media, they often did it to provide updates to their support system. Keeping people updated on their treatment experiences led AYA to receive visible social support:

I made a post about when we first came here and my dad was, um, pushin' me in a wheelchair and he went off the sidewalk and that is my favorite one that I actually shared [...] I wasn't really nervous, I posted it and I put the caption about how I got here and what's happened, so really everybody knows that follows me on Instagram [...] they mostly said that they're very supportive and that they love that picture cuz it was so funny (Female, 16, Solid Tumor)

AYA were thoughtful about the social support they received. All types of social support meant something to the AYA, but the meaning was not always positive. For one AYA, the social support was only temporarily uplifting. He reviewed his social media page and acknowledged that several posts on his wall were people tagging him in fundraisers. He said:

Everyone I've met, or have known in my lifetime has been really supportive- ever since the beginning, and that's great n all but at the same time [...] I wouldn't have all these people sendin' me stuff, wouldn't have all these people wantin' to talk to me every day [...] I wouldn't have all these people buying t-shirts with my name or... wristbands... or

doin' all these fundraisers for me... I wouldn't have all that if that wasn't here in the position that I am [...] I mean it, it feels good ta have that support, don't get me wrong, but at the same time... I uh... kind of take it as like, pity. (Male, 18, Leukemia-2)

Fortunately, other AYA found long-lasting positive meaning from the social support they received online. For example, the support a different AYA received during treatment seemed to confirm something larger about his sense of self:

Facebook, I post about, um, my diagnosis and you know the support that I have and... there was one time where- I actually, like, started to see how people were happy to see my smile. So, I had posted a picture and I didn't really smile cuz I didn't like the way that I smile- I didn't like the way that I looked, and so they were like, "why are you not smilin'" like, they were comin' for me in the comments about me not smilin'... I was like... is that what people actually look at me for? a smile and a hug, is literally what they look for in me, cuz I have a great personality. (Male, 18, Leukemia-1)

Several AYA also shared that finding cancer-related content through social media was an indirect source of social support. Indirect social support was meaningful in a different way. Rather than highlighting the support the AYA had within their already established social network, it validated their illness experience on a broader scale.

I just saw her like one day pop up [...] I found her on TikTok, yes, but uh... she has a website and all that kind of stuff and I think she's writing a book as well which is really cool- she got a- she had a... a... a, in the uterus I think... she had a tumor in the uterus [...] I don't see her a lot, it just like comes up sometimes and I just scroll on her page and see what she's posted, but she posts sometimes, uh, like just about her life and all that

kind of stuff and, like, her friends and stuff but [...] then she'll sometimes talk about, like, her experiences with, like, chemotherapy and um how it like made her feel [...] She just puts it into, like, words a lot better than I ever could- like- to somebody else (Female, 15, Brain Tumor)

Posting about cancer online provided AYA with a way to share updates and access social support from their social network. AYA who shared about cancer online interpreted social support on social media in complex ways. Importantly, even those who chose not to share about their cancer experiences online could find cancer-related social support through social media.

The aim for this initial qualitative phase was to better contextualize which social and illness variables are important for understanding self-perception in AYA with cancer. As described in Chapter 3, a building approach to mixed methods integration is the process of using the results from one phase of the study to inform data collection in the following phase (Fetters et al., 2013). As such, the building integration in this study used the qualitative results to inform the quantitative variable selection for the next phase of this study. The quantitative variables will be discussed in the next section on quantitative analysis and results.

Quantitative Results

The purpose of the quantitative phase of this study was to further understand the importance of the social and illness variables identified following the qualitative phase on self-perception in AYA with cancer. In Chapter 2, consideration was given to the impact of cancer, coping, and social support on self-perception in AYA. After exploring the phenomenon of social interaction on social media after diagnosis with eight AYA with cancer in the initial qualitative phase of this study, coping was not identified as an important variable for self-perception in

AYA with cancer, but cancer impact and social support were. Additionally, engagement habits on social media emerged as a new important variable to consider.

Table 2 (below) represents the building integration for this mixed methods study, connecting themes from the qualitative results to the variable selection for the quantitative phase of this study. As noted above, engagement habits, social support, and cancer impact emerged as the concepts relevant to explore for self-perception in AYA with cancer. Only some subscales of self-perception were selected to explore, again based on the results of the qualitative themes. The relevant self-perception subscales for this study are physical appearance, close friendships, social competence, peer friendships/social acceptance, and global self-worth/ self-esteem. The measures assessing each of these concepts were used for data collection in the quantitative phase of this study and are indicated in Table 2. The following sections describe the quantitative phase of the current study, which explored the relevance of engagement habits, social support, and cancer impact on self-perception in AYA treated for cancer.

Table 2*Building Integration of Qualitative Findings into Quantitative Variable Selection*

Qualitative Findings	Quantitative Variables	Relevant Questionnaire	Mixed Interpretation on Self-Perception
Purpose: To understand AYA social interaction on social media since diagnosis	Purpose: To identify social and illness variables important for understanding AYA self-perception		Purpose: To explore the subscales of self-perception associated with social interaction on social media and social/illness variables
Theme 1: AYAs enact active and passive engagement depending on the social media platform	<u>Engagement Habits</u> (frequency of use; by platform)	OSSS	Physical Appearance SPP(-A, -EA) Close Friendships SPP(-A)
Theme 2: AYAs' social media habits change due to treatment experiences	<u>Engagement Habits</u> (frequency of use) <u>Cancer Impact</u> (practical) <u>Social Support</u>	OSSS MSPSS YACIS	Social Competence SPP(-A) Peer Friendships/Social Acceptance SPP(-EA)
Theme 3: AYAs evaluate and protect their self-image, privacy, and time	<u>Engagement Habits</u> <u>Social Support</u> <u>Cancer Impact</u> (psychological)	OSSS MSPSS YACIS CES	Global Self-Worth/Self-Esteem SPP(-A, -EA)
Theme 4: AYAs access and interpret the meaning of social support that they receive online	<u>Social Support</u>	OSSS MSPSS	

Participants and Data Collection

This study was activated in April 2020. Shortly after activation, all social-behavioral research protocols at the institution were placed on voluntary hold due to the COVID-19 pandemic. No participants had been enrolled or were impacted at that time. Revisions to the protocol were made to include updated procedures for recruitment and participation given COVID-19 social distancing requirements. Examples of revisions included including operations to carry out procedures remotely (i.e., collect data in virtual formats and to adjust recruitment according to study staff availability). These revisions were submitted to the IRB in July 2020 and the study was reactivated in September 2020. A list of eligible patients was reviewed, and study team members approached patients during their already-scheduled visits to the hospital or by phone call to inquire regarding interest in participation.

From September 2020 through July 2021, eighteen participants were enrolled in the quantitative arm of the study. However, after reviewing their questionnaire responses, only eleven participants had completed enough of the measures to be included in the current analysis. Attempts were made to contact participants and encourage completion of the questionnaires, after which one additional response was included bringing the total sample to twelve. This total sample includes three off-therapy patients. Although the original intent was to explore a sample of AYA on therapy, given the small sample size a decision was made to include all of the responses available.

Acknowledging that the nature of a smaller study sample means adapting the analytical strategy, changes were made to the research question for this study phase. Instead of asking about relationships among several variables, which would require more advanced statistical

analyses, the updated research question became: What social and illness factors are most important for self-perception in AYA treated for cancer?

Data Preparation

The data were imported from the electronic database where responses were collected into an excel file. The file was initially cleaned by removing all protected information and creating dummy participant IDs. Then, irrelevant questionnaire data were deleted from the spreadsheet. For example, the coping questionnaire mentioned in Chapter 3 was deemed irrelevant for the current study given what was learned in the qualitative phase. For this reason, the RSQ was deleted from the total dataset. Only the demographic and medical factors, the OSSS, MSPSS, YACIS, CES, and SPPA/EA items remained. Each scale was cleaned by organizing the variables within the excel spreadsheet; some scales required items to be removed or recoded. Nominal variables were dummy coded. For example, gender was recoded such that *Female* = 1 and *Male* = 2.

OSSS. The OSSS contains two sections, the first assessing frequency of interaction across several platforms and the second assessing feelings of support while interacting online (see Appendix C). Nick et al. (2018) recommends researchers adapt their use of the scale based on their sample, noting the rapid changes occurring in social media spaces. Indeed, while the original measure assesses engagement habits on more than 10 social media platforms, AYA in the qualitative phase of this study reported using four key platforms most often when interacting with others: Facebook, Snapchat, Instagram and TikTok. Because the qualitative sample informed the selection of quantitative variables, only the responses for these items were kept for analysis.

YACIS. The YACIS assesses practical impact of cancer on five separate domains, but only one item is relevant for the purpose of this study, item number 2 (see Appendix D). This item assesses practical impact of cancer on ability to engage in social activities. All other items were removed.

SPPA/EA. The SPPA/EA scores items from 1-4, with higher scores indicating higher self-perception. Some items require reverse scores, and Harter (2012b, 2016) includes a scoring manual for researcher use. Each questionnaire is comprised of several subscales. Subscales are intended to be analyzed independently from one another, and it is not recommended to combine scores for a total score of self-perception. Subscales for physical appearance, close friendships, social competence, and global self-worth were kept for the SPPA. Subscales for physical appearance, peer friendships/social acceptance, and global self-esteem were kept for the SPPEA. Items were checked and recoded according to the provided scoring manuals (see Appendices F and G).

Treatment of Missing Data. Each participant strand was checked for missing data. At this time, there were a total of five missing items for five different participants. For the one missing item on the SPPA, recommendations from Harter (2012b) were followed and a prorated, subscale average was calculated for that participant by summing the scores to the other items completed in that subscale and calculating the mean of those scores. For the OSSS, there were three separate instances of a participant missing a single item. After consulting with the measurement developer, a decision was made to calculate the median score for that item and use this value for the item score. This common-point imputation was performed using the median given the small sample size. Finally, one participant was missing one item on the CES.

Consistent with treatment of missing data in similarly scored scales, common-point imputation using the median was performed for this item.

Data Analysis

After cleaning and preparation, all data were saved and imported into IBM SPSS Statistics 25 for further analysis. Prior to statistical analysis, variables were reviewed within SPSS and some variables were recoded into new, different variables. A discussion of the variables that were created are in the following paragraphs. A summary of the results related to these variables occurs in the next section and are reported in Table 3 in Appendix H.

Demographics. A new variable for age category was created from reported age in years, dichotomizing all participants into one of two groups, where *adolescents* = 0 (ages 15-18 years) and *young adults* = 1 (ages 19 years or older). Similarly, a new variable representing months since diagnosis was created from reported length of time since diagnosis in months, dichotomizing all participants into one of two groups, where *diagnosis less than or equal to 5 months* = 0 and *6 months or more* = 1.

Social Support, Cancer Impact, and Self-Perception Scales. Six new variables were created from the OSSS. The first five were derived from the first set of questions in the measure, assessing frequency of use on various apps. For each of the apps included in this analysis (Facebook, Snapchat, Instagram, and TikTok) a frequency of use dichotomous variable was created. Since participants self-reported their frequency of use on each platform with 0 = *never*, 1 = *rarely*, 2 = *sometimes*, 3 = *pretty often*, and 4 = *a lot*, a low frequency group by platform was created for participants who reported scores ranging from 0 to 2 and a high frequency group by platform was created for participants who reported scores at 3 or 4. Overall low and high

frequency groups were also identified by creating a dichotomized overall engagement variable after calculating a composite mean score from the sum of scores across platforms.

Nick et al. (2018) acknowledges that there are no “low” or “high” cutoffs for social media use or for social support, but recommends evaluating the scores continuously, at relative levels within the sample. As such, a dichotomous variable was also created for relatively low support and high support based on the overall mean score. Meaning, participants with lower OSSS mean scores than the average were defined as reporting low support and participants with higher OSSS mean scores than the average were defined as reporting high support. The range of total scores was 16.00-158.00.

Composite scores were calculated at the total and subscale levels for the MSPSS. A new variable was created for the MSPSS dichotomizing participants into high and low reported social support groups, similar to the OSSS. Zimet et al. (1988) describe a procedure for trichotomizing participants into low, medium, and high support groups to ensure equal numbers of participants but caution on issues where some groups may have a skewed value (i.e., the low support group actually reports high means). Given the small sample size for this analysis, a decision was made to dichotomize rather than trichotomize participants; based on the overall mean score, participants with lower mean scores than average were defined as reporting low support and participants with higher mean scores than average were defined as reporting high support. Although participants in the low support group may also report a moderately high mean social support score, it is important to note that low support group indicates lower reported support relative to others within the sample. The range of scores was 4.67 to 7.00.

For the CES, a mean score of all items was calculated for each participant, and a sample mean for the scale was used as the mid-point for dichotomizing a high and low levels of

psychological cancer impact within the sample. Mean scores were also calculated from the YACIS item for each participant. A calculated sample mean for the item was used as the mid-point for dichotomizing a high and low levels of practical cancer impact within the sample. The low and high cancer impact groups should also be considered relatively within the sample. The range of scores for the CES was 3.00 to 4.90 and for the YACIS was 1 to 10.

Results

The quantitative analysis yielded two types of results. The first set of results provide a descriptive summary of the data set and explore important demographic factors. The second set of results examines the importance of engagement habits, social support, and cancer impact for self-perception among adolescents and young adults. This study intended to perform more advanced analyses to examine associations between these factors, but the analytic strategy was limited by the sample size. The implications for these limitations are discussed further in Chapter 5.

Descriptive statistics were computed for demographic categories. A total of twelve participants were included in the sample (58.3% female; 50% white). 58.3% of participants were adolescents, 75% were on therapy and 50% were diagnosed in the past 5 months. The sample was representative of several diagnostic groups, including leukemia/lymphoma (66.7%), solid tumor, and brain tumor. Given the small sample size of this study, no advanced group comparisons can be done. However, observations of mean scores and standard deviations are reported for each concept (i.e., social support, cancer impact, and self-perception) by demographic factor (i.e., gender, age category, engagement habits, treatment status, and months since diagnosis). These results can be found in Table 3 in Appendix H. Notable findings are discussed below.

Social Support by Demographic Factor. Social support is the first concept explored and was assessed using the MSPSS and the OSSS. As a reminder, MSPSS assessed multidimensional social support both comprehensively and across three subscales: friend, family, and significant other. The OSSS assessed online social support both comprehensively and across four subscales: esteem/emotional, social companionship, informational, and instrumental. Key demographic differences by social support factors are discussed in the sections below.

Gender. For multidimensional social support, male AYA reported higher mean scores for the significant other subscale compared to females, but female AYA reported higher mean scores on the family and friend subscales compared to males. For online social support, males reported higher mean scores in all subscales except for informational support.

Age Category. Young adults reported higher multidimensional mean scores compared to adolescents except for on the significant other subscale. Young adults reported a higher total mean score for online social support, but adolescents reported higher mean scores in the esteem/emotional and social companionship subscales. However, the mean scores within the esteem/emotional and social companionship subscales are more similar than the mean scores reported by adolescents and young adults in the informational and instrumental subscales.

Engagement Habits. Those reporting higher frequency of online engagement also reported lower mean scores in multidimensional social support except for on the friend subscale. For online social support, AYA reporting higher engagement habits also reported higher total mean scores, with the highest mean reported in the esteem/emotional subscale. The widest gap in reported means occurred in the social companionship subscale.

Treatment Status. On-treatment AYA reported higher means in multidimensional social support except on the friend subscale, in which off-treatment AYA reported higher mean scores. In fact, off-treatment AYA consistently reported higher means for social support online, at the total and subscales levels. The largest differences in reported mean scores occurred within the informational and instrumental support subscales.

Months Since Diagnosis. AYA farther away from diagnosis compared to the rest of the sample reported higher means in overall multidimensional social support and in the friend subscale of multidimensional social support, but AYA closer to diagnosis reported higher mean scores on family and significant other subscales. Consistently, those farther away from diagnosis reported higher mean scores in online social support, especially on instrumental and informational support subscales.

Cancer Impact by Demographic Factor. Cancer impact is the second concept explored and was assessed using the YACIS and the CES. As a reminder, the YACIS assessed practical impact of cancer whereas the CES assessed psychological impact of cancer. Key demographic differences by cancer impact are discussed below.

For both practical and psychological impact of cancer, males reported lower mean scores compared to females. Young adults reported higher mean scores in psychological impact whereas adolescents reported higher mean scores in practical impact of cancer. AYA who reported higher frequency of online engagement also reported higher mean scores in psychological cancer impact, whereas participants who reported lower frequency of online engagement reported higher mean scores in practical cancer impact. Off-therapy participants reported higher mean scores in both types of cancer impact. However, when looking at the length of time since diagnosis, participants who are 6 months or more from diagnosis reported higher

mean scores in psychological impact but those who are 5 months or less from diagnosis reported higher mean scores in practical cancer impact.

Self-Perception by Demographic Factor. Self-perception is the final concept explored and was assessed using the SPPA and SPPEA. As a reminder, the SPPA assessed self-perception among adolescents using the physical appearance, close friendships, social competence, and global self-worth subscales. The SPPEA assessed self-perception among young adults using the physical appearance, peer friendships/social competence, and global self-esteem subscales. Key demographic differences by self-perception subscales are discussed below.

Gender. For adolescents, male AYA reported higher mean scores on all self-perception subscales except for physical appearance. Among young adults, males reported higher mean scores on all self-perception subscales except for peer friendships/social acceptance.

Age Category. Both the SPPA and the SPPEA include subscales of physical appearance and of global self-worth. Adolescents reported higher mean scores in global self-worth compared to young adults' reports of global self-esteem.

Engagement Habits. For adolescents, those with higher frequency of online engagement reported higher mean scores across all self-perception subscales. For young adults, those reporting lower engagement online also reported higher mean scores across all subscales. The highest overall mean score for adolescents was in the social competence subscale, with high-engaged adolescents reporting even higher mean scores than low-engaged teens. The highest overall mean score for young adults was among low-engaged young adults in the peer friendships/social acceptance subscale.

Treatment Status. Only the young adult group of participants had AYA who were both on- and off-treatment. Those on-treatment reported higher means on self-perception subscales. It is important to interpret this cautiously, as only three young adult participants were off-treatment. Finally, when observing scores from adolescents who are 6 months or more from diagnosis, they report higher mean scores consistently across self-perception subscales, and especially in the close friendships subscale and the least high mean score for these participants is on the physical appearance subscale. For young adults, the opposite is true, with those closer to diagnosis reporting higher mean scores in all self-perception subscales, but especially on the peer friendships/social acceptance subscale.

Importance of Engagement Habits, Social Support, and Cancer Impact for Self-Perception Among Adolescents and Young Adults. Additional observations considered the relevance of social and illness variables (i.e., engagement habits, social support, and cancer impact) on subscale means of self-perception. The four subscales of self-perception included in the analyses for adolescents were physical appearance, close friendships, social competence, and global self-worth. The three subscales of self-perception included in the analyses for young adults were physical appearance, peer friendships/social acceptance, and global self-worth/self-esteem.

Engagement Habits and Self-Perception. Adolescents who engage less frequently online consistently reported lower mean scores across all four domains of self-perception as compared to adolescents who engage more frequently online. However, when broken down by platform, the opposite is true on the global self-worth subscale for three platforms (Facebook, Instagram, and TikTok). On these platforms, adolescents who reported higher online engagement reporting lower mean scores. Adolescents who reported high engagement on TikTok appear especially

susceptible to lower mean scores in self-perception subscales of close friendships and of social competence.

For young adult patients, the opposite is true about social media engagement levels and self-perception mean scores compared to adolescents, such that those who engage less often reported higher mean scores in all self-perception subscales. When broken down by platform, this remains true for low-engaged users on Instagram and TikTok but is not true on Facebook. On Facebook, participants reporting higher engagement report higher means in self-perception subscales. Notably, TikTok remains an interesting platform for young adults. The differences between high and low mean scores on self-perception subscales are greatest on this platform.

Social Support and Self-Perception. Adolescents who reported higher levels of social support, both multidimensional and online, also reported higher mean scores in all self-perception subscales. This is especially true in the peer and social domains of close friendships and social competence. Opposite observations also appear for young adults compared to adolescents in social support mean scores on self-perception subscales. For example, young adults who reported lower levels of social support, both multidimensional and online, reported higher self-perception means on most subscales. The only subscale where this is not the case, is on global self-worth regarding level of multidimensional social support, where those reporting higher scores of social support also reported higher mean global self-worth scores.

Cancer Impact and Self-Perception. Adolescents who reported higher cancer impacts, both practical and psychological, report higher mean scores in self-perception subscales. This observation was especially true on the peer and social domains of self-perception, close friendships and social competence. For young adults, a lower reported cancer impact (both

practical and psychological) reported higher self-perception means on all subscales, but especially on physical appearance and on global self-esteem.

Observations of mean scores and standard deviations are reported for adolescents in Tables 4 and for young adults in Table 5.

Table 4*Social/Illness Variables and Self-Perception in Adolescents*

		SPPA (<i>N</i> = 7)			
		<i>M (SD)</i>			
		Physical Appearance	Close Friendship	Social Competence	Global Self-Esteem
Total		2.63 (.80)	2.77 (.90)	3.06 (.86)	2.97 (.56)
<i>Engagement Habits</i>					
Facebook	High	2.70 (.42)	2.80 (.28)	3.20 (.28)	3.10 (.14)
	Low	2.60 (.95)	2.76 (1.09)	3.00 (1.04)	2.92 (.67)
Snapchat	High	1.80	3.00	3.60	2.80
	Low	2.77 (.77)	2.73 (.98)	2.97 (.91)	3.00 (.61)
Instagram	High	2.68 (.58)	3.08 (.54)	3.32 (.30)	3.24 (.38)
	Low	2.50 (1.56)	2.00 (1.41)	2.40 (1.70)	2.30 (.14)
TikTok	High	3.30 (.42)	2.80 (.28)	3.30 (.42)	2.70 (.42)
	Low	2.36 (.77)	2.76 (1.09)	2.96 (1.01)	3.08 (.61)
	High	2.68 (.83)	2.72 (1.09)	2.96 (1.01)	2.92 (.64)
	Low	2.50 (.99)	2.90 (.14)	3.30 (.42)	3.10 (.42)
<i>Social Support</i>					
Multidimensional					
	High	2.70 (.77)	3.25 (.50)	3.55 (.10)	3.05 (.60)
	Low	2.53 (.99)	2.13 (.99)	2.40 (1.04)	2.87 (.61)
Online					
	High	2.85 (.76)	3.15 (.60)	3.45 (.30)	3.00 (.59)
	Low	2.33 (.90)	2.27 (1.10)	2.53 (1.17)	2.93 (.64)
<i>Cancer Impact</i>					
Practical					
	High	2.90 (.77)	3.20 (.54)	3.45 (.30)	3.10 (.62)
	Low	2.27 (.81)	2.20 (1.06)	2.53 (1.17)	2.80 (.53)
Psychological					
	High	2.70 (.77)	3.25 (.50)	3.55 (.10)	3.05 (.60)
	Low	2.53 (1.00)	2.13 (1.00)	2.40 (1.04)	2.87 (.61)

Table 5*Social/Illness Variables and Self-Perception in Young Adults*

		SPPEA (<i>N</i> = 5)		
		<i>M</i> (<i>SD</i>)		
		Physical Appearance	Peer Friendships/ Social Acceptance	Global Self-Esteem
Total		2.40 (.88)	2.95 (.93)	2.30 (.65)
<i>Engagement Habits</i>				
	High	2.08 (1.01)	2.75 (1.15)	2.00 (.66)
	Low	2.88 (.53)	3.25 (.71)	2.75 (.35)
Facebook	High	2.50 (*)	3.75 (*)	3.00 (*)
	Low	2.38 (1.01)	2.75 (.94)	2.13 (.60)
Snapchat	High	2.40 (.88)	2.95 (.93)	2.30 (.65)
	Low			
Instagram	High	2.08 (1.01)	2.75 (1.15)	2.00 (.66)
	Low	2.88 (.53)	3.25 (.71)	2.75 (.35)
TikTok	High	1.63 (.88)	2.13 (.53)	1.63 (.18)
	Low	2.92 (.38)	3.50 (.66)	2.75 (.25)
<i>Social Support</i>				
Multidimensional				
	High	2.25 (1.15)	2.75 (1.00)	2.33 (.76)
	Low	2.63 (.53)	3.25 (1.06)	2.25 (.71)
Online				
	High	2.00 (1.41)	2.88 (1.59)	2.13 (.88)
	Low	2.67 (.52)	3.00 (.66)	2.42 (.63)
<i>Cancer Impact</i>				
Practical				
	High	2.08 (1.01)	2.75 (1.15)	2.00 (.66)
	Low	2.86 (.53)	3.25 (.71)	2.75 (.35)
Psychological				
	High	2.08 (1.01)	2.75 (1.15)	2.00 (.66)
	Low	2.86 (.53)	3.25 (.71)	2.75 (.35)

Mixed Methods

The purpose of the mixed methods research design for this study was first, at the methods level, to identify relevant social and illness variables through qualitative investigation among a representative sample of AYA. Second and most importantly, the purpose of mixed methods is to integrate the analysis and interpretation of qualitative and quantitative findings in order to understand how stories from AYA with cancer inform understanding about the role of social interaction on social media for self-development.

The mixed methods research question was, how do stories from AYA with cancer about social interactions on social media inform our understanding of self-perceptions in many AYA treated for cancer? To address this question, joint display tables were created with side-by-side representations of the qualitative and quantitative findings. Joint display tables were created for each relevant variable identified in the building approach to integration following the initial qualitative analysis (refer to Table 2).

Mixed Methods Interpretations

The important variables identified for this study were engagement habits, social support, and cancer impact. As such, the observations of these variables on self-perception subscale outcomes are examined in Tables 6, 7, and 8. Each table is set up with two intents: organizational intent and analytic intent (Haynes-Brown & Fetters, 2021). Following Haynes-Brown & Fetters (2021), the organizational intent was to display the results from the qualitative analysis alongside the results from the quantitative analysis while the analytic intent was to interpret the ways in which the quantitative data confirmed, expanded, or were inconsistent with the qualitative findings (Haynes-Brown & Fetters, 2021).

Organizationally, each table aims to provide an effective display of relevant qualitative findings alongside relevant quantitative findings. The qualitative findings listed within the tables highlight important aspects of AYA stories that relate to the quantitative variable explored (i.e., engagement, social support, or cancer impact). Profiles of high and low scores for each variable were created in the quantitative section and displayed with contrasting colors in relation to their reported mean score on self-perception subscales. Analytically, each table served to display key points for how the quantitative and qualitative findings related to one another. The outcome of these analyses for each concept are described in the sections below.

Joint Display Table: Engagement Habits and Self-Perception. Mixed methods integration for the role of engagement on self-perception reveals that the quantitative results confirm, expand, and were inconsistent with the qualitative findings. The quantitative results confirm the qualitative findings such that engagement differs across platforms and those platforms have different meanings on self-perception domains. One example of this, is that Snapchat was revealed in the qualitative findings as a platform used to connect directly with peers, and in the quantitative results high engagement on Snapchat is also reported along with higher reported means in the close friendships and social competence subscales of self-perception compared to the physical appearance or global self-worth subscales. Another way the quantitative results confirm the qualitative findings is by reinforcing how low engagement may protect some aspects of self-perception among AYA with cancer. For instance, in the qualitative findings, AYA patients reported that self-image is a motivation for low engagement on social media. This is also apparent in the quantitative results, such that low-engaged young adults also reported higher physical appearance self-perception than high-engaged young adults.

The quantitative results expand the qualitative results in three keyways. First, comparing the findings in the joint display table reveals that engagement frequency does play an important role in social competence and peer friendship self-perception domains. Second, the differences in social media platform engagement are important for understanding self-perception in AYA. Third, there appear to be age-related differences in the role of engagement habits and of platform preference on self-perception domains.

The quantitative results differ from the qualitative results in one way. Some AYA in the qualitative sample reported lower engagement on social media due to social separation from friends and a lack of close friendships during treatment. But the quantitative sample reveals high mean scores in peer and social domains of self-perception regardless of engagement frequency.

This range of interplay between the qualitative and quantitative results highlight the important and unique role that social media engagement has on self-perception among AYA with cancer. Important aspects of engagement to consider include frequency of use, platform preference, and age-related differences in outcomes. See Table 6 for the side-by-side display of qualitative findings and quantitative findings related to engagement habits and self-perception.

Table 6

Side-by-Side Joint Display of Engagement Habits and Self-Perception (SP)

Qualitative Notes on Engagement Habits	Quantitative Results on Self-Perception (SP)																																																													
<p>Theme 1</p> <ul style="list-style-type: none"> • AYAs use many different SM platforms • AYAs differ in the platforms that they use most often • Each SM platform offers unique reasons for engagement • Some platforms are used more for direct peer connection, whereas others are used more for passive entertainment • Snapchat, Facebook, and Instagram are more commonly used for peer connection; TikTok is more commonly used for media consumption 	<div style="display: flex; justify-content: space-around;"> <div data-bbox="548 415 1241 841"> <p style="text-align: center;">High Engagement by SM Platform on SPPA Subscales</p> <table border="1"> <caption>High Engagement by SM Platform on SPPA Subscales</caption> <thead> <tr> <th>Subscale</th> <th>Overall</th> <th>Facebook</th> <th>Snapchat</th> <th>Instagram</th> <th>TikTok</th> </tr> </thead> <tbody> <tr> <td>Physical Appearance</td> <td>2.7</td> <td>1.8</td> <td>2.7</td> <td>3.3</td> <td>2.7</td> </tr> <tr> <td>Close Friendships</td> <td>2.8</td> <td>3.0</td> <td>3.1</td> <td>2.8</td> <td>2.7</td> </tr> <tr> <td>Social Competence</td> <td>3.2</td> <td>3.6</td> <td>3.3</td> <td>3.3</td> <td>2.9</td> </tr> <tr> <td>Global Self-Worth</td> <td>3.1</td> <td>2.8</td> <td>3.2</td> <td>2.7</td> <td>2.9</td> </tr> </tbody> </table> </div> <div data-bbox="1268 415 1961 841"> <p style="text-align: center;">Low Engagement by SM Platform on SPPA Subscales</p> <table border="1"> <caption>Low Engagement by SM Platform on SPPA Subscales</caption> <thead> <tr> <th>Subscale</th> <th>Overall</th> <th>Facebook</th> <th>Snapchat</th> <th>Instagram</th> <th>TikTok</th> </tr> </thead> <tbody> <tr> <td>Physical Appearance</td> <td>2.6</td> <td>2.8</td> <td>2.5</td> <td>2.4</td> <td>2.5</td> </tr> <tr> <td>Close Friendships</td> <td>2.8</td> <td>2.7</td> <td>2.0</td> <td>2.8</td> <td>2.9</td> </tr> <tr> <td>Social Competence</td> <td>3.0</td> <td>3.0</td> <td>2.4</td> <td>3.0</td> <td>3.3</td> </tr> <tr> <td>Global Self-Worth</td> <td>2.9</td> <td>3.0</td> <td>2.3</td> <td>3.1</td> <td>3.1</td> </tr> </tbody> </table> </div> </div>		Subscale	Overall	Facebook	Snapchat	Instagram	TikTok	Physical Appearance	2.7	1.8	2.7	3.3	2.7	Close Friendships	2.8	3.0	3.1	2.8	2.7	Social Competence	3.2	3.6	3.3	3.3	2.9	Global Self-Worth	3.1	2.8	3.2	2.7	2.9	Subscale	Overall	Facebook	Snapchat	Instagram	TikTok	Physical Appearance	2.6	2.8	2.5	2.4	2.5	Close Friendships	2.8	2.7	2.0	2.8	2.9	Social Competence	3.0	3.0	2.4	3.0	3.3	Global Self-Worth	2.9	3.0	2.3	3.1	3.1
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<p>Theme 2</p> <ul style="list-style-type: none"> • There are physical and social impacts of cancer treatment on social media engagement • Engagement changes in two main ways: frequency and activity-type • Social changes offline lead to higher frequency for entertainment motivations for peer connection reasons • AYA can engage in ways that shares their cancer experience with others 	<div style="display: flex; justify-content: space-around;"> <div data-bbox="548 935 1241 1360"> <p style="text-align: center;">High Engagement by SM Platform on SPPEA Subscales</p> <table border="1"> <caption>High Engagement by SM Platform on SPPEA Subscales</caption> <thead> <tr> <th>Subscale</th> <th>Overall</th> <th>Facebook</th> <th>Snapchat</th> <th>Instagram</th> <th>TikTok</th> </tr> </thead> <tbody> <tr> <td>Physical Appearance</td> <td>2.1</td> <td>2.5</td> <td>2.4</td> <td>2.1</td> <td>1.6</td> </tr> <tr> <td>Peer Friendships/Social Acceptance</td> <td>2.7</td> <td>3.7</td> <td>2.9</td> <td>2.7</td> <td>2.1</td> </tr> <tr> <td>Global Self-Esteem</td> <td>2.0</td> <td>3.0</td> <td>2.3</td> <td>2.0</td> <td>1.6</td> </tr> </tbody> </table> </div> <div data-bbox="1268 935 1961 1360"> <p style="text-align: center;">Low Engagement by SM Platform on SPPEA Subscales</p> <table border="1"> <caption>Low Engagement by SM Platform on SPPEA Subscales</caption> <thead> <tr> <th>Subscale</th> <th>Overall</th> <th>Facebook</th> <th>Snapchat</th> <th>Instagram</th> <th>TikTok</th> </tr> </thead> <tbody> <tr> <td>Physical Appearance</td> <td>2.9</td> <td>2.4</td> <td>2.9</td> <td>2.9</td> <td>2.9</td> </tr> <tr> <td>Peer Friendships/Social Acceptance</td> <td>3.2</td> <td>2.8</td> <td>3.2</td> <td>3.2</td> <td>3.5</td> </tr> <tr> <td>Global Self-Esteem</td> <td>2.8</td> <td>2.1</td> <td>2.8</td> <td>2.8</td> <td>2.8</td> </tr> </tbody> </table> </div> </div>		Subscale	Overall	Facebook	Snapchat	Instagram	TikTok	Physical Appearance	2.1	2.5	2.4	2.1	1.6	Peer Friendships/Social Acceptance	2.7	3.7	2.9	2.7	2.1	Global Self-Esteem	2.0	3.0	2.3	2.0	1.6	Subscale	Overall	Facebook	Snapchat	Instagram	TikTok	Physical Appearance	2.9	2.4	2.9	2.9	2.9	Peer Friendships/Social Acceptance	3.2	2.8	3.2	3.2	3.5	Global Self-Esteem	2.8	2.1	2.8	2.8	2.8												
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Table 6

Side-by-Side Joint Display of Engagement Habits and Self-Perception (SP)

<p><u>Theme 3</u></p> <ul style="list-style-type: none">• AYA engagement frequency may be low in order to protect their self-image, privacy, and time	<ul style="list-style-type: none">• Overall engagement:<ul style="list-style-type: none">○ Adolescents with high engagement report higher means on SP domains than adolescents with low engagement.○ Young adults with low engagement report higher means on SP domains than young adults with high engagement.• Platform differences:<ul style="list-style-type: none">○ For adolescents, TikTok is a platform that relates to different trends in SP reported means. On TikTok, adolescents with high engagement reported <i>lower</i> means in three out of four SP domain (close friendship, social competence, and global self-worth) compared to adolescents with low engagement on the platform.○ Adolescents with high engagement on Facebook and Instagram also report lower means on the SP domain of global self-worth compared to low-engaged adolescents on those same platforms.○ For young adults, Facebook is a platform that differs from the rest with high-engaged users reporting higher means on all SP domains.○ On TikTok, young adults report the greatest differences by high- and low-engaged users on SP subscale mean scores.○ Snapchat is typically a platform that engages both adolescents and young adults at high rates and has the highest SP mean scores in social/peer domains• The highest reported means within SP domains regarded social competence for adolescents and peer friendships/social acceptance for young adults.<ul style="list-style-type: none">○ High-engaged adolescents reported highest means within the SP social competence domain, whereas low-engaged young adults reported highest means within the SP peer friendships/social acceptance domain.
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Joint Display Table: Social Support and Self-Perception. Mixed methods integration for the role of the role of social support on self-perception reveals that the quantitative results confirm and expand the qualitative findings. One way that the quantitative results confirm the qualitative results is that online social support is important to consider as a factor that may relate to self-perception of physical appearance. Additionally, multidimensional and online social support are important contexts for understanding self-perception among AYA, particularly in peer and social domains. An example of this is that, in adolescents, high levels of social support report higher means in these domains.

The quantitative results also expand the understanding of the qualitative results. For instance, in the qualitative sample, we learned that high levels of social support can lead to complicated feelings among AYA. The quantitative results reveal that there are young adults with high levels of social support who still report low mean scores in self-perception domains. The understanding of this finding is enhanced by integrating these two results, such that high levels of social support may be complex and not always correspond to high levels of social and peer self-perception.

Understandably, social support is most important for peer and social domains of self-perception. New insights include the age-related differences in outcomes, and differences in the role of online social support as it relates to physical appearance. Further integration for social support is represented in Table 7, below.

Table 7

Side-by-Side Joint Display of Social Support and Self-Perception (SP)

Qualitative Notes on Social Support	Quantitative Results on Self-Perception (SP)																																														
<p><u>Theme 2</u></p> <ul style="list-style-type: none"> Treatment often leads to physical and social distance of AYA to their offline social networks, but they can remain connected to social networks through online communication <p><u>Theme 3</u></p> <ul style="list-style-type: none"> AYAs consider others' feedback on self-image when deciding to post or not to post cancer-related content on SM Highly active or responsive online social networks can be burdensome to AYAs' time and privacy <p><u>Theme 4</u></p> <ul style="list-style-type: none"> SM offer AYA with cancer access visible social support from their offline social network during treatment Online social support during treatment can make AYA feel positively and negatively about themselves or their situation SM provide opportunities for AYA to receive social support online from a broader network than their offline network 	<p style="text-align: center;">Social Support by SPPA Subscales</p> <table border="1"> <caption>Estimated Data for Social Support by SPPA Subscales</caption> <thead> <tr> <th>Subscale</th> <th>Multidimensional-High</th> <th>Multidimensional-Low</th> <th>Online-High</th> <th>Online-Low</th> </tr> </thead> <tbody> <tr> <td>Physical Appearance</td> <td>2.7</td> <td>2.5</td> <td>2.8</td> <td>2.3</td> </tr> <tr> <td>Close Friendships</td> <td>3.2</td> <td>2.1</td> <td>3.1</td> <td>2.2</td> </tr> <tr> <td>Social Competence</td> <td>3.5</td> <td>2.4</td> <td>3.4</td> <td>2.5</td> </tr> <tr> <td>Global Self-Worth</td> <td>3.0</td> <td>2.8</td> <td>3.0</td> <td>2.9</td> </tr> </tbody> </table> <p style="text-align: center;">Social Support by SPPEA Subscales</p> <table border="1"> <caption>Estimated Data for Social Support by SPPEA Subscales</caption> <thead> <tr> <th>Subscale</th> <th>Multidimensional-High</th> <th>Multidimensional-Low</th> <th>Online-High</th> <th>Online-Low</th> </tr> </thead> <tbody> <tr> <td>Physical Appearance</td> <td>2.3</td> <td>2.6</td> <td>2.0</td> <td>2.7</td> </tr> <tr> <td>Peer Friendships/Social Acceptance</td> <td>2.8</td> <td>3.2</td> <td>2.9</td> <td>3.0</td> </tr> <tr> <td>Global Self-Esteem</td> <td>2.4</td> <td>2.3</td> <td>2.1</td> <td>2.4</td> </tr> </tbody> </table>	Subscale	Multidimensional-High	Multidimensional-Low	Online-High	Online-Low	Physical Appearance	2.7	2.5	2.8	2.3	Close Friendships	3.2	2.1	3.1	2.2	Social Competence	3.5	2.4	3.4	2.5	Global Self-Worth	3.0	2.8	3.0	2.9	Subscale	Multidimensional-High	Multidimensional-Low	Online-High	Online-Low	Physical Appearance	2.3	2.6	2.0	2.7	Peer Friendships/Social Acceptance	2.8	3.2	2.9	3.0	Global Self-Esteem	2.4	2.3	2.1	2.4	<ul style="list-style-type: none"> Adolescents who report higher levels of multidimensional and of online social support also report higher means in all SP domains. <ul style="list-style-type: none"> Highest means are reported in close friendships and social competence SP domains. Adolescents who report lower levels of online social support also report the lowest means within the physical appearance domain of SP. Young adults who report lower levels of multidimensional and online social support report higher means in SP domains. <ul style="list-style-type: none"> One exception is in the global self-esteem domain, in which higher levels of multidimensional social support report higher SP means. Highest means are reported in the peer friendships/social acceptance SP domain. Young adults who report lower levels of online social support also report the highest means within the physical appearance domain of SP. Mean scores in the global self-worth/esteem domain are most similar across all levels of reported social support, both multidimensional and online for both adolescents and young adults.
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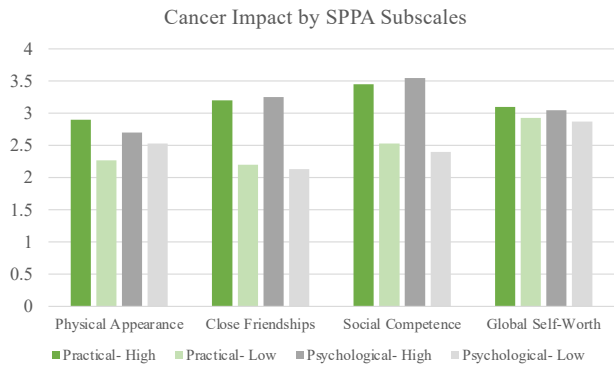
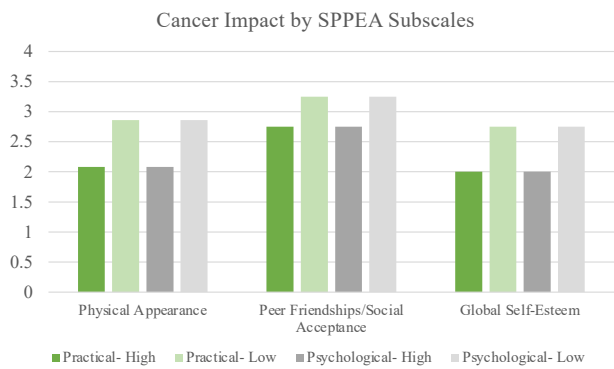
Joint Display Table: Cancer Impact and Self-Perception. Mixed methods integration for the role of the role of cancer impact on self-perception reveals that the quantitative results are confirmatory but also contain areas of disagreement with the qualitative results. The quantitative results confirm the qualitative findings by demonstrating how cancer can impact AYA in physical, practical, and psychosocial ways. Additionally, the quantitative results confirm that cancer impact plays a role in AYA social relationships.

The quantitative findings also differ from the qualitative findings. While, in the qualitative sample, some AYA feared their diagnosis would negatively change their social relationships and so they altered their social interaction, the quantitative findings reveal that AYA who reported high impact of cancer also report high means in peer and social domains of self-perception. This is especially true among adolescents.

The findings reveal that cancer impact may be most important to consider for its role on physical appearance and global self-esteem. In other words, AYA with cancer may continue to have strong social competence and friendships along with a high evaluation of cancer impact. Further discussion of the integration of results related to cancer impact are found in Table 8, below.

Table 8

Side-by-Side Joint Display of Cancer Impact and Self-Perception (SP)

Qualitative Notes on Cancer Impact	Quantitative Results on Self-Perception (SP)																																													
<p><u>Theme 2</u></p> <ul style="list-style-type: none"> • There are physical and social impacts of cancer treatment on social interaction with friends • Cancer underlies some aspects of social interaction off- and online, including the content AYA share online <p><u>Theme 3</u></p> <ul style="list-style-type: none"> • AYA feel physical and social burdens related to their diagnosis and treatment • AYAs consider how their diagnosis will change their relationships 	<div style="display: flex; justify-content: space-between;"> <div style="width: 45%;">  <p style="text-align: center;">Cancer Impact by SPPA Subscales</p> <table border="1"> <caption>Data for SPPA Subscales</caption> <thead> <tr> <th>Subscale</th> <th>Practical-High</th> <th>Practical-Low</th> <th>Psychological-High</th> <th>Psychological-Low</th> </tr> </thead> <tbody> <tr> <td>Physical Appearance</td> <td>2.9</td> <td>2.3</td> <td>2.7</td> <td>2.5</td> </tr> <tr> <td>Close Friendships</td> <td>3.2</td> <td>2.2</td> <td>3.3</td> <td>2.1</td> </tr> <tr> <td>Social Competence</td> <td>3.5</td> <td>2.5</td> <td>3.6</td> <td>2.4</td> </tr> <tr> <td>Global Self-Worth</td> <td>3.1</td> <td>2.9</td> <td>3.0</td> <td>2.8</td> </tr> </tbody> </table> </div> <div style="width: 45%;"> <ul style="list-style-type: none"> • Adolescents who report higher impacts of cancer (both practical and psychological) also report higher means in all SP domains <ul style="list-style-type: none"> ○ Highest means are reported in the close friendships and social competence domains • Among young adults, those who report a lower impact of cancer (both practical and psychological) report higher means in all SP domains <ul style="list-style-type: none"> ○ Highest means are reported in the peer friendships/social acceptance domains </div> </div> <div style="margin-top: 20px;">  <p style="text-align: center;">Cancer Impact by SPPEA Subscales</p> <table border="1"> <caption>Data for SPPEA Subscales</caption> <thead> <tr> <th>Subscale</th> <th>Practical-High</th> <th>Practical-Low</th> <th>Psychological-High</th> <th>Psychological-Low</th> </tr> </thead> <tbody> <tr> <td>Physical Appearance</td> <td>2.1</td> <td>2.8</td> <td>2.1</td> <td>2.8</td> </tr> <tr> <td>Peer Friendships/Social Acceptance</td> <td>2.7</td> <td>3.2</td> <td>2.7</td> <td>3.2</td> </tr> <tr> <td>Global Self-Esteem</td> <td>2.0</td> <td>2.7</td> <td>2.0</td> <td>2.7</td> </tr> </tbody> </table> </div>	Subscale	Practical-High	Practical-Low	Psychological-High	Psychological-Low	Physical Appearance	2.9	2.3	2.7	2.5	Close Friendships	3.2	2.2	3.3	2.1	Social Competence	3.5	2.5	3.6	2.4	Global Self-Worth	3.1	2.9	3.0	2.8	Subscale	Practical-High	Practical-Low	Psychological-High	Psychological-Low	Physical Appearance	2.1	2.8	2.1	2.8	Peer Friendships/Social Acceptance	2.7	3.2	2.7	3.2	Global Self-Esteem	2.0	2.7	2.0	2.7
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Summary

The process of building side-by-side joint display tables helped the analytic process for the mixed methods question for this study: how do stories from AYA with cancer about social interactions on social media inform our understanding of self-perceptions in many AYA treated for cancer? By teasing out the qualitative and quantitative findings relevant for each social or illness variable (i.e., engagement habits, social support, and cancer impact) and for self-perception, deeper understanding of these relationships could be explored for the current sample. Importantly, there were several times that the quantitative results confirmed or expanded qualitative findings, but there were also times where the quantitative results differed from what was learned in the qualitative sample.

While this study was exploratory in nature, and it is important to interpret these comparisons with caution, the mixed methods results provide discussion for describing the roles of engagement, social support, and cancer impact on social interaction on social media and self-perception outcomes in AYA with cancer. A more detailed discussion including implications, limitations, and recommendations for future research are found in Chapter 5.

CHAPTER 5

Discussion

Introduction

For AYA with cancer, tasks of social and identity development are challenging (Zebrack, 2011). In order to improve AYA psychosocial care, we must identify the aspects of cancer and of social relationships that are important for self-development. This study contributes to our understanding by characterizing social interaction and self-development among AYA with cancer in many ways. First, stories from AYA on treatment for cancer show that social media is a key area where they interact with others. Further, these stories highlight how cancer experiences shape their engagement habits, perceptions of social support, and evaluation of cancer impact. Therefore, in order to understand how social interaction on social media relates to self-development in AYA, this study reveals the importance of first exploring the roles of engagement, social support, and cancer impact among a sample of AYA with cancer. Drawing on this information, the current study assessed the relevance of these variables on reported self-perception in AYA treated for cancer. Finally, an integrated review of these concepts through joint display tables provided a more comprehensive interpretation of the interplay between social interaction on social media and self-perception in AYA with cancer.

Social Media Experiences among AYA with Cancer

For all AYA, social interaction is a key process informing self-development. Social interaction is an exercise in presenting the self to others, receiving feedback, and making self-evaluations (Goffman, 1959). For AYA with chronic illness, self-presentation involves consideration of new concepts, like whether (or how much) to disclose about their diagnosis and how they perceive others will respond to such disclosures (Woodgate et al., 2020). One avenue

for social interaction where AYA with cancer have more control over their self-presentation, is on social media (Daniels et al., 2021).

Prior to this study, very few studies examined the role of normative social media use among AYA with cancer. Instead, studies focused on the usefulness of social media to deliver health-related interventions or to connect AYA with other cancer peers (Keim-Malpass et al., 2016; Pereira et al., 2019). When typical use was explored, it revealed that social media is a preferred space for AYA with cancer to maintain their friendships and that they are thoughtful about others' reactions to their self-presentation online (Daniels et al., 2021; Marôpo & Jorge, 2017). The results from this study importantly expand the literature by identifying factors that play into AYA cancer patients' self-disclosure online and how they manage their interactions with others during treatment. Some factors to consider are engagement (both frequency and platform activity) cancer impact (both practical and psychological) and social support (both offline and online).

Engagement and Social Media Interaction. AYA shared stories about changing engagement habits during cancer treatment. First, AYA patients described changes in frequency of social media. Importantly, not all AYA experienced the same changes. Whereas some patients saw increased frequency to either connect with friends or to pass time, others decreased their use overall. This variability in usage has been demonstrated in other studies among AYA with cancer (Daniels et al., 2021). While frequency changes are interesting, it is perhaps more important to consider those changes as they occur on different platforms. In the current study, all AYA shared understandings about the different purposes for different social media platforms. Regardless of how an AYA with cancer chose to engage on social media, they were likely to access more direct connection with peers when using Snapchat, Facebook, or Instagram compared to TikTok.

Although a popular platform, TikTok may offer a different type of support to AYA with cancer than other platforms which promote social interaction with close friends who also exist in offline networks.

These findings relate to literature about social media engagement among AYA with chronic illness. Although not specifically related to cancer, van der Veldan and El Emam (2013) similarly found that AYA with chronic illnesses engage often on social media platforms which are used to connect with peers, and use different platforms for different reasons (like YouTube for media consumption). The social norm of enacting different types of engagement on different platforms may indeed be explained by the social networks attached to those platforms. One study found that healthy AYA are more likely to engage in intentional self-presentation on platforms with networks of close friends, such as on Snapchat, compared to on platforms with broader networks, such as Instagram (which has both close friends and others) (Him et al., 2020). The findings from the current study regarding engagement habits lead to new questions about the importance of changes in engagement frequency on certain platforms compared to others while navigating social changes during treatment.

Cancer Impact and Social Media Interaction. In addition to changes in frequency and type of engagement, evaluations of the impact of cancer were also importantly related to social interaction on social media. Practical evaluations of cancer impact, such as physical and social distance to peers due to long stays at the hospital made AYA think about their social interaction differently. At times, they shared updates about their experiences because of this impact or reflected that they felt emotionally distant as a result of the separation. Cancer impact also shaped social media interaction by influencing the content AYA shared which, although not always explicitly, often referred to aspects of the cancer experience. It is interesting to consider

how self-presentation of cancer-related content may relate to selective self-presentation among AYA with cancer. Selective self-presentation among healthy AYA is the practice of editing self-presentation to convey a specific message to others (Calvin, 2020).

AYA were thoughtful about the amount of time it would take to interact with others during their treatment. Not surprisingly, this finding reinforces what is known about offline disclosure among AYA: it can be exhausting (Woodgate et al., 2020). Additionally, despite frequent social interaction, chronic illness is impactful in shaping AYA with chronic illness thoughtfulness about privacy when interacting with others online (van der Velden & El Emam, 2013). Even more importantly, the psychological impact of cancer played a role in comfort with social interaction on social media. AYA in the current study who reported feeling vulnerable about their self-image were hesitant to interact with others online. This is consistent with literature that cancer patients are sensitive about their body image (see Daniels et al., 2021) and that perceived judgements of others influence the content shared and frequency of engagement among healthy AYA (Duffy & Chan, 2019; Seehafer, 2017; Yau & Reich, 2019). It is curious whether limiting social interaction on social media because of self-image concerns related to cancer could be temporarily protective during cancer treatment.

Social Support and Social Media Interaction. The stories shared by AYA in the current study demonstrate the complexities of social support during treatment for cancer. Social media provide opportunities for AYA to connect with their offline support systems and for AYA to access new support networks of cancer peers. Most AYA reported accessing social support online via direct interaction, while some AYA who interact less often online still found social support from observing others' content that related to their life experiences. This finding is different from literature regarding social interaction online by AYA with chronic illness who

reported not seeking out others with similar diagnosis on Facebook (van der Velden & El Emam, 2013).

AYA received visible social support online through likes, comments, and direct communication. Consistent with literature on social media interaction among healthy AYA, this type of feedback indicates peer approval and support (Calvin, 2020). However, social support online does not always make AYA feel positively. In fact, AYA with cancer interpret social support in ways that may make them feel negatively about their situation or make them feel burdened. While literature from healthy AYA demonstrates that commenting on online posts shared by others is a way to show care, and that when others do that to them it shows support for them/their situation (see Gibson & Trnka, 2019), the stories shared in this study reveal a more complex relationship. AYA with cancer in the current study said online social support during treatment can emphasize the situation they are in and that they may interpret it as pity. Additionally, receiving social support online can feel taxing due to feeling like they should return the support with gratitude.

Self-Perception Among AYA with Cancer

Prior to this study, the evidence regarding self-perception and AYA with cancer was also limited. However, Harter (2012b) self-development research career has examined aspects of self-perception in populations of healthy AYA and describes it as a multidimensional construct. The way self-perception is evaluated is by comparing and contrasting objective and subjective assessments of competence in certain domains (Harter, 2012b). In other words, AYA are asked questions about their perceptions of themselves and about their perceptions of others within the same domain.

Past studies on self-perception in children with cancer demonstrate awareness of their self-image and social isolation (Sadruddin & Hameed-ur-Rehman, 2013). Among the AYA in this study, physical appearance remains a low scoring domain of self-perception, especially among adolescents. This finding is again evidenced in a study by Hörnquist et al. (2015), where AYA cancer survivors score lower on self-perception scores related to physical appearance, peers, and global self-esteem. The results from the current study confirm this finding: among young adults in this sample, 3 out of 5 were off-treatment and self-perception scores were lowest in physical appearance and in global self-esteem.

Engagement, Cancer Impact, and Social Support on AYA Self-Perception. Looking at observed mean scores on self-perception in AYA from the current study indicates the important roles of engagement frequency and platform preference, cancer impact, and social support for understanding self-perception.

The findings from the current study showed that adolescents who reported higher engagement online also reported higher mean scores on self-perception, whereas young adults who reported low engagement online reported higher mean scores on self-perception. Looking to the literature, it is important to consider the difference in development between an adolescent and a young adult to better understand this result. Developmentally, young adults are more likely to have increased independence in several domains (i.e., residential, financial, occupational, familial) (Arnett, 2000). Therefore, young adults may have more freedom to engage with their social networks offline. For instance, young adults may not require permission from adults to see their friends, they may have independent means of transit to access their friend groups, and may integrate several different social networks from school, work, and spousal relationships. Comparatively, adolescents may have strong offline friendships but those more often exist in the

school-based peer culture (Arnett, 2000). This means adolescents may be more reliant on social media as a means of connecting with their friends when not in face-to-face settings, like school. When considering self-perception related to friendships and social competence, this may help explain the finding in the current study that adolescents with higher engagement report higher means in self-perception compared to young adults.

Echoing the qualitative findings of this study, there are platform differences that are reported relative to reported self-perception mean scores. Particularly for the peer and social subscales of self-perception, high engagement appears most important for high self-perception on platforms with closer social networks, like Snapchat and Instagram. Users reporting high engagement on Snapchat also reported higher means on the peer and social subscales of self-perception than users reporting high engagement on Instagram. This finding confirms the information that Snapchat is a platform for closer-network interaction than Instagram (Him et al., 2020). TikTok, a newer platform that rose to popularity in 2020, is a platform that should be further examined in future research as no trend appears for this platform, but it still appears important in differences between high and low engagement on self-perception, particularly related to physical appearance and to global self-worth.

Social support is another variable important to consider in relation to self-perception. The findings from this study emphasize the role of online social support in self-perception of physical appearance among adolescence, such that those who report lower online social support also report lower physical appearance self-perception scores. This is consistent with literature indicating the susceptibility of adolescents to peer judgement online related to their self-image (Chua & Chang, 2016; de Vries et al., 2016). Interestingly, this finding is different for young

adults, such that those reporting lower levels of online social support also report higher means in physical appearance self-perception.

It is important to note that social support plays the least important role for global self-worth. Regardless of whether users reported high or low multidimensional and online social support scores, mean scores of global self-worth/esteem were reported in similar ways. This finding is encouraging, as it provides insight that social support may be most important for more modifiable domains of self-perception, like physical appearance or peer/social acceptance, compared to a more consistent domain, like global self-worth/esteem.

Finally, the practical and psychological impacts of a cancer diagnosis are certainly relevant to consider as they relate to self-perception in AYA. Prior to this study, only one study examined the role of cancer-related stressors on multifaceted self-perception in youth with cancer (Hockenberry-Eaton et al., 1995). The current study provides updated insight to the impact of the cancer experience on self-perception domains. Whereas Hockenberry-Eaten et al. (1995) show lower self-perception among youth with high cancer-related stressors, the current study demonstrates how cancer can be highly stressful while simultaneously important for higher self-perception. This could be because the current study only looks at some domains of self-perception, including peer friendships and social competence. Knowing that a cancer diagnosis can make people feel closer to their friends (see McDonnell et al., 2020), the findings from the current study reiterate that a higher cancer impact may also correspond to higher reported self-perception in social domains.

It is important to note that this finding is, however, untrue for the young adults in the current study. Similar to the other variables important for self-perception, young adults express different scores. For young adults, those who reported lower cancer impact reported higher self-

perception in all domains. One possible explanation for this is that young adults typically have a more formed identity compared to adolescents who are only at the beginning stages of identity formation (Arnett, 2000). Therefore, young adults evaluating a higher impact of cancer may experience more disruption to their self-perception.

Key Interpretations of Social Media Interaction and Self-Perception

Developmental researchers, parents, educators, and health care providers all acknowledge the importance of social media interactions in typical AYA self-development today, but the narrative about this relationship is often overly generalized or exaggerated (Davis et al., 2019). Unfortunately, this leads to misconceptions regarding the power of social media on self-development among AYA and removes important contextual and agentic considerations that affect specific populations of AYA. For instance, whereas a key finding discussed in social media research today may be that social comparison online negatively relates to self-esteem and body image, this may *only* be true, or may *especially* be true, for certain groups of AYA, like girls (Calvin, 2020). Therefore, the current study importantly interprets the findings of social interaction on social media and self-perception related to this sample of AYA with cancer. As a pilot study, the interpretations are valuable for describing the factors of cancer that may help explain the relationship between social media interactions and self-perceptions in future studies among AYA with cancer.

The integrated mixed methods analysis in the current study cannot explain direct relationships or predict outcomes related to social media interaction and self-presentation in AYA with cancer. Nevertheless, comparing the quantitative observations with the qualitative themes from this study provides valuable insight for future research that seeks to describe the intersections of variables that matter for complex psychosocial environments. Although this

study only shares preliminary results, there are three key interpretations from the current study that provide important context for studying social media interaction and self-perception in this population.

First, changes in social media engagement may be the most important factor of social interaction online for explaining self-perception in AYA with cancer. When considering the role of social interaction online for self-perception in AYA with cancer, the current study first focused on the role of self-presentation via sharing of images. However, as AYA shared stories about their social media interactions during treatment for cancer, they more often described their overall engagement habits, including their frequency of social media use and their motivations underlying platform preferences. The quantitative phase of this study explored these factors. Several observations were made regarding the role of engagement, including differences in reported means among high- and low-engaged social media users and among users of different platforms. The integrated analysis revealed that the quantitative findings reinforced, expanded, and differed from the qualitative findings. Clearly, there is much to explore regarding engagement and self-perception.

Second, even with a larger sample of participants, it is important not to draw generalizations about the relationship between social interaction on social media and self-perception among an entire sample of AYA with cancer. Similarly, researchers should consider a bidirectional relationship between these concepts. Social media is a dynamic and rapidly changing space for social engagement. Therefore, it is first important to define social interaction on social media through dialogue with users at that time. AYA in the current study described social norms on social media, which helped contextualize the interpretation of observed variability, for example in platform differences. Further, it is important to review potential

differences in sub-groups of AYA, as the mixed methods findings consistently reported different considerations based on age.

Third, it is important to acknowledge the complicated roles of social and illness variables. Meaning, for AYA with cancer, variables like social support or cancer impact may hold different meanings related to their online engagement than what is expressed at face-value. For instance, one might initially expect high levels of social support to be important for high levels of self-perception. But the findings from the qualitative portion of this study revealed how high levels of social support online are not always positive. Similar findings were apparent for the role of cancer impact. Acknowledging the lived experience of such factors among AYA with cancer can help researchers make more specific interpretations.

Implications

The findings from this study offer methodological and practical implications for research on social interactions on social media and on self-perception for AYA with cancer.

Methodological

This mixed methods study followed an exploratory sequential design, beginning with a qualitative phase followed by a quantitative phase. The findings from this study imply the importance of narrative inquiry, of photo-elicited interviews, and of the mixed methods research approach. Developmentally focused social media research calls for more qualitative work in this space (Davis et al., 2020). The qualitative phase indeed launched the ideas for the line of inquiry pursued in this dissertation. Embracing a narrative inquiry approach allowed me to listen to the stories shared by AYA and observe the ways in which AYA created meaning throughout the interviews. Narrative inquiry also aligns well with social media research, because it acknowledges the continuous evolution of meaning as the story is told in new spaces (Clandinin

& Huber, 2010). As social media interaction continues to evolve, so will the meaning of the stories shared by AYA in the current study. Additionally, framing the data collection through a narrative inquiry lens placed the AYA in the position of sharing what was most important to them, rather than responding to questions about what I perceived to be most important. At a time when AYA are often stripped of independence and told how to participate in their health care journey, it felt important to provide AYA a space where they could be experts in sharing about a topic relevant to them.

Photo-elicitation interview methods are recommended for evoking memories and helping participants reflect through a visual-verbal process (Tinkler, 2014). Throughout the research process, several AYA forgot to bring images with them to the interview, and others had difficulty identifying a single photo to discuss. Some researchers identify difficulty engaging participants in photo-elicitation when the prompt is highly emotional (Tinkler, 2014). Although the prompt for photo-elicitation in the current study was emotional, it seemed the challenge for engaging participants in photo-elicitation was more regarding feasibility of selecting a photo. When social media photos were brought up in the interviews, even when a physical photo representation was not, they were helpful to participants in reflecting on the meaning of feedback they received and on their process for sharing that image. Additionally, the analytical process was helped by referring back to the photos shared by AYA. This importantly reveals that, although I encountered some challenges with this type of data collection, it is valuable to take the time to clarify the purpose of photo-elicitation and help participants prepare for this portion of the interview.

Finally, despite the limitations with recruitment discussed in Chapter 4 and below, the mixed methods design allowed for meaningful interpretation of findings. The ability to compare

and contrast observations of mean scores related to self-perception in AYA with cancer in relation to the qualitative findings about their social media interactions allowed for deeper insight into the variables which are important to consider in future studies. The mixed methods research design is especially useful for building context around a unique study sample, such as AYA with cancer, and for research related to concepts which are not extensively found in the current evidence base (Bryman, 2006; Regnault et al., 2018). Social media interaction and self-perception are independently understudied among AYA with cancer, and even more so in relation to one another. The research design of the current study begins to address this gap in pilot exploratory research that will contribute to the development of future studies.

Practical

The practical implications from the current study inform psychosocial care for AYA with cancer. Given the dearth of literature linking the concepts of self-presentation and self-development via social interaction on social media and self-perception, this study provides novel insights for health care providers to consider when working with this population. While this study could not examine direct relationships or predictors of self-perception outcomes, it did reveal which social and illness factors (engagement habits, social support, and cancer impact) are important to consider when researching these concepts ahead.

The results from the current study emphasize that, for AYA with cancer, there is no universal experience. AYA with cancer share similar social experiences but may respond to those experiences differently and even interpret the meaning of those experiences differently. Additionally, due to the complicated nature of cancer experiences and of social media interactions, there are several possible constructions of factors that, when taken together, provide different explanations for self-perception. A goal in psychosocial health care is to identify

populations at risk for experiencing negative outcomes and to examine the efficacy of interventions to mitigate these outcomes. This study highlights that there is no one-sized-fits-all approach for navigating social interaction on social media during treatment for cancer. Instead, this study suggests the importance of acknowledging these topics with patients, listening to their individual experiences, and providing care that addresses their unique needs.

While no common assessment or intervention can be recommended from the current study, the findings do reveal certain areas of AYA social interaction which may be important to explore with AYA cancer patients. Some AYA from the current study reported hesitancy sharing about their cancer experience with others online, for reasons of protecting privacy and self-image, as well as protecting time. Since AYA report wanting more support in disclosure practices (see Kent et al., 2013) providing AYA with the insights from this study may help them decide what is best for them. Simply being a provider who is willing to discuss possible strategies for social media interaction could be helpful.

When working with AYA with cancer, psychosocial providers should continue to embrace a patient-centered approach, knowing that what we learn from one perspective is never the full picture for all patients. Each AYA brings a unique set of experiences, personality traits, habits, and preferences, which guide the ways in which social interaction will inform their self-development. Importantly, the results from this study support the notion that thorough assessment of psychosocial development in AYA with cancer requires attention to AYA social interaction online.

Limitations

This study, although insightful in its comprehensive look at social interaction and self-development in AYA treated for cancer, has some important limitations to consider. The concept

for this project was developed prior to the COVID-19 pandemic. As mentioned in Chapter 4, the enrollment process was greatly impacted by the pandemic. The research questions were slightly more detailed at this study's inception. Specifically, the quantitative aim for this study was to examine the associations of certain social and illness factors on outcomes of self-perception. Due to the challenges faced with data collection, the goals for this study shifted into a more exploratory descriptive study. As such, the interpretations regarding observed means are cautious not to generalize the experiences of these samples to larger groups of AYA with cancer. It is also important to note that, given the limited sample, all "low" and "high" groups within variables are relatively small, and since they are further divided between adolescents and young adults, the number of the sub-sample is sometimes as small as 2. By dichotomizing the groups around the mean score, what is considered "high" and "low" should only be interpreted as such relative to the sample. That being said, the range of scores were broad and the findings provide interesting insights for future research.

Recommendations for Future Research

Unfortunately, the findings from this study also reveal relatively low mean scores on several self-perception domains. This study highlighted only the most salient domains of self-perception related to the reported social/illness variables shared by AYA in the qualitative interviews (physical appearance, close friendships, social competence, peer friendships/social acceptance, and global self-worth/esteem). It is important that future studies explore self-perception scores across all domains to ensure that these domains are the most affected (Harter 2012a). Additionally, further research comparing self-perception in groups of AYA with cancer and in groups of healthy AYA will be important for benchmarking high levels of self-perception

(Harter, 2012a). This is especially important to examine given that AYA with cancers' self-perceptions are amenable to change in response to interventions (Wurz et al., 2021).

Mixed methods studies are useful for testing and exploring factors which can be later analyzed in more specific or advanced detail (Creswell & Plano Clark, 2018). The current study does exactly this, by identifying relevant variables for exploration within a specific group of AYA with cancer. While the literature on social experiences and identity development is vast for AYA with cancer, few studies explore the interplay of these factors, and rarely describe the social experiences in the context of social media. Future studies can build from the current study to explore longitudinal outcomes and to examine the interrelationships between several variables. Longitudinal research design may offer more insight into the changes AYA with cancer experience over time related to their social interaction and self-perception. This study raises the question, as AYA with cancer work through treatment, are there changes that occur in social media interaction that may affect their self-perception at the end of treatment?

Finally, studies exploring the relationship between social media interaction and self-development outcomes in AYA with cancer should consider the complex interrelationship among variables identified in the current study. For instance, engagement and social support or cancer impact taken together may be more interesting for self-perception than in isolation. In studies regarding physical appearance self-perception in youth with cancer, social support is a moderating factor for positive adjustment (Fan & Eiser, 2009). It is possible that some of the factors identified in the current study may have moderating effects in the relationship between social interaction on social media and self-perception, but studies will need to recruit larger samples to assess this thoroughly.

Latent variable mixture modeling is one statistical approach used in psychology that examines groupings of individuals for certain variable outcomes (Berlin et al., 2014). In the context of such a unique sample, AYA with cancer, latent profile analyses based on engagement habits, platform preferences, levels of social support, and levels of cancer impact may provide insight into the extent to which these variables play a role in self-development outcomes. This type of approach would be helpful for identifying groups of AYA patients that are at risk for experiencing negative outcomes in self-development, and more specifically individualized approaches for supporting these groups of patients.

Conclusion

The current study provides a starting point for describing the relationship between social media interactions and self-perceptions in AYA with cancer. It identifies relevant variables to consider under which social interaction may change or may be affected during the cancer trajectory. It reveals the importance of incorporating questions about social media use in psychosocial assessment during treatment for cancer. It also suggests the importance of further studying self-perception among AYA treated for cancer. Following integrated analysis of qualitative and quantitative results regarding social media interaction and self-perception in a small sample of AYA treated for cancer, several key interpretations were made. First, it is important to examine social media engagement habits when studying self-perception in AYA with cancer. Second, it is important to recognize the individuality among AYA with cancer in the role of social media interaction and in self-perception outcomes. Third, it is important to acknowledge the complicated roles of social and illness factors for AYA with cancer. Although health care providers are concerned for the well-being and improved care for AYA with cancer, several discrepancies in AYA and health care provider perceived psychosocial outcomes remain

(Kaal et al., 2021). For this reason, gathering insights from AYA with cancer regarding their experiences can help clarify areas where improvements can be made psychosocial care.

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Appendix A Qualitative Interview Guide

Example questions to be used during the qualitative interview with AYA participants are below. Listed numerical questions are key “guideposts” that we will seek to cover, while bulleted questions/statements are potential prompts if needed to engage participants further.

Of note, Question 10 will be photo-elicited and will require participants to select and talk about a post that they’ve shared on social media. Participants who do not use social media, or those who are not comfortable sharing this post will still be able to complete the interview.

1. Tell me about your diagnosis
 - a. How do you typically tell people about your diagnosis and hospital experience?
2. Tell me about the friends that you are closest to right now, or the friends that you spend the most time with currently.
 - a. Tell me about the person or people you feel closest to (best friend).
 - b. How do your friends get along with one another? (one group vs. multiple)
 - c. What kinds of things do you do as a group?
 - d. How did you meet your friends? Where did you meet them?
 - e. Probe on romantic relationships if mentioned.
3. In what ways do you think your friendships have changed since being diagnosed with cancer?
 - a. What about changes in the way you interact with one another?
 - b. Any challenges experienced in keeping friends since being diagnosed?
 - c. Describe how you keep in touch with your friends during treatment.
 - d. Has your romantic relationship changed?
4. Tell me about any friends that you’ve made since arriving at the hospital.
 - a. What kinds of challenges have you experienced in making friends since being diagnosed?
 - b. How important is it to you that you make friends while you’re at the hospital?
5. Think about your home friends and your hospital friends... Tell me about their similarities. What about the differences that you notice between them?
6. What types of social media do you use?
 - a. How often do you typically use social media?
 - b. Tell me briefly about your social network- the people that you follow and the people who follow you online.
 - i. Accounts private/public
 - ii. If multiple accounts, ask a little more about that
 - c. What sorts of activities do you do on social media? (i.e., direct messaging, sharing photos, streaming videos, sharing “stories”).
 - d. Do you follow any cancer-related accounts/hashtags?
 - e. *If they say no social media-* clarify, ask more questions, do you have any accounts? Why no social media? Connect with friends online in any way? Have you used it previously? Share pictures with friends via text?
7. What things do you like and dislike about social media?
8. How has your use of, or attitude toward, social media changed since diagnosis?

- a. If previously mentioned that has multiple accounts- differences in posts you make?
 - b. Are there any differences in the accounts/hashtags that you follow? (e.g., cancer-related accounts).
9. In thinking about the posts you've shared on social media since diagnosis, what is one photo/post that stands out to you?
 - a. Please describe the picture you are showing me, including any caption/hashtags you used.
 - b. What platform did you share this post on?
 - c. Tell me about your decision to post this photo.
 - d. What types of feedback did you receive on this post?
 - i. Is there a specific comment that stands out?
 - ii. Did you expect this feedback at the time that you posted it?
 - e. What is your reason for choosing this photo to talk about over any other photo you've posted since diagnosis?
- If the chosen post wasn't the first post about diagnosis- ask this question:*
 - f. Tell me about the first time you posted about your diagnosis or hospital experiences on social media.
 - g. What do you remember feeling or thinking before making that post?
 - h. What kind of feedback did you get after making that post?
10. If we were designing a program for adolescents and young adults here at the hospital, what are some of the things related to friendships that you think are most important for us to focus on?
 - a. Summarize what they've talked about- challenges in these areas- are there things we could do here to support you?
 - b. Provide examples of things we did pre-pandemic
11. Is there anything else about your experience that I haven't ask you yet that I should have?
12. Is there anything else that we've talked about today that you'd like to discuss further?

Appendix B
Multidimensional Scale of Perceived Social Support (MSPSS)
 Zimet et al. (1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the “1” if you **Very Strongly Disagree**
 Circle the “2” if you **Strongly Disagree**
 Circle the “3” if you **Mildly Disagree**
 Circle the “4” if you are **Neutral**
 Circle the “5” if you **Mildly Agree**
 Circle the “6” if you **Strongly Agree**
 Circle the “7” if you **Very Strongly Agree**

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

Significant Other Subscale: Items 1, 2, 5, & 10
 Family Subscale: Items 3, 4, 8, & 11
 Friends Subscale: Items 6, 7, 9, & 12

Appendix C
Online Social Support Scale (OSSS)
 Nick et al. (2018)

Most sites, apps, services, and games on the Internet can be used in lots of different ways and for different purposes. We're interested in how much you use these online spaces to **connect or interact with other people**.

This means we **are** interested in how much you use these online spaces to talk with people, post, comment, like, send messages, game with others, etc.

How much do you use the following sites, apps, services, or games to **connect or interact with other people**?

	Never	Rarely	Sometimes	Pretty Often	A Lot
Facebook	0	1	2	3	4
Instagram	0	1	2	3	4
Twitter	0	1	2	3	4
Snapchat	0	1	2	3	4
Tumblr	0	1	2	3	4
YouTube	0	1	2	3	4
TikTok	0	1	2	3	4
Pinterest	0	1	2	3	4
VSCO	0	1	2	3	4
Reddit	0	1	2	3	4
Kik	0	1	2	3	4
LinkedIn	0	1	2	3	4
Google+	0	1	2	3	4
Chat Services (e.g., WhatsApp, GroupMe)	0	1	2	3	4
Whisper	0	1	2	3	4
Ask.fm	0	1	2	3	4
Dating sites/apps (e.g., Bumble, Tinder)	0	1	2	3	4
First person shooter games (e.g., Call of Duty)	0	1	2	3	4
Battle arena games (MOBAs: e.g., League of Legends)	0	1	2	3	4
Sports/fighting/racing games (e.g., FIFA, Street Fighter, Mario Kart)	0	1	2	3	4
Role-playing games (RPGs: e.g., World of Warcraft)	0	1	2	3	4
Other:	0	1	2	3	4
Other:	0	1	2	3	4

Other:	0	1	2	3	4
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Now, thinking about the online spaces you use above. Rate **how often** the following things have happened for you **while you interacted with others online** over the last two months.

	Never	Rarely	Sometimes	Pretty Often	A Lot
1. People show that they care about me online	0	1	2	3	4
2. Online, people say or do things that make me feel good about myself	0	1	2	3	4
3. People encourage me when I'm online	0	1	2	3	4
4. People pay attention to me online	0	1	2	3	4
5. I get likes, favorites, upvotes, views, etc. online	0	1	2	3	4
6. I get positive comments online	0	1	2	3	4
7. When I'm online, people tell me they like the things I say or do	0	1	2	3	4
8. Online, people are interested in me as a person	0	1	2	3	4
9. People support me online	0	1	2	3	4
10. When I'm online, people make me feel good about myself	0	1	2	3	4
11. When I'm online, I talk or do things with other people	0	1	2	3	4
12. People spend time with me online	0	1	2	3	4
13. People hang out and do fun things with me online	0	1	2	3	4
14. Online, I belong to groups of people with similar interests	0	1	2	3	4
15. People talk with me online about things we have in common	0	1	2	3	4
16. Online, I connect with people who like the same things I do	0	1	2	3	4
17. I am part of groups online	0	1	2	3	4
18. When I'm online, people joke and kid around with me	0	1	2	3	4
19. People relate to me through things I say or do online	0	1	2	3	4

20. Online, people make me feeling like I belong	0	1	2	3	4
21. When I'm online, people give me useful advice	0	1	2	3	4
22. Online, people provide me with helpful information	0	1	2	3	4
23. If I had a problem, people would help me online by saying what they would do	0	1	2	3	4
24. Online, people would tell me where to find help if I needed it	0	1	2	3	4
25. People help me learn new things when I'm online	0	1	2	3	4
26. People offer suggestions to me online	0	1	2	3	4
27. People tell me things I want to know online	0	1	2	3	4
28. When I'm online, people help me understand my situation better	0	1	2	3	4
29. If I had a problem, people would share their point of view online	0	1	2	3	4
30. People help me see things in new ways when I'm online	0	1	2	3	4
31. People online would help me with money or other things if I needed it	0	1	2	3	4
32. When I'm online, people help me with school or work	0	1	2	3	4
33. Online, people help me get things done	0	1	2	3	4
34. If I needed a hand doing something, I go online to find people who will help out	0	1	2	3	4
35. Online, people offer to do things for me	0	1	2	3	4
36. Online, people help me with causes or events that I think are important	0	1	2	3	4
37. When I'm online, people have offered me things I need	0	1	2	3	4
38. When I need something, I go online to find someone who might lend it to me	0	1	2	3	4
39. When I need a hand with school or work things, I get help from others online	0	1	2	3	4
40. I contact people online to get help or raise money for things I think are important	0	1	2	3	4

Nick et al, 2018 – score by summing items; article has means/sd for community & college samples. Esteem/Emotional Support (1-10); Social Companionship (11-20); Informational Support (21-30); Instrumental Support (31-40)

Appendix D
Young Adult Cancer Impact Scale (YACIS)
Schwartz & Drotar (2004)

On a scale of 1 to 10, how much do you feel your cancer or the cancer treatment has affected your educational achievement?

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
did not affect at all extremely affected it

On a scale of 1 to 10, how much do you feel your cancer or the cancer treatment has affected your participation in social activities or your ability to interact socially?

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
did not affect at all extremely affected it

On a scale of 1 to 10, how much do you feel your cancer or the cancer treatment has interfered with achieving your career goals?

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
did not interfere at all extremely interfered with it

On a scale of 1 to 10, how much do you feel your cancer or the cancer treatment has affected your pursuit of or ability to maintain romantic relationships?

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
did not affect at all extremely affected it

On a scale of 1 to 10, how much do you feel your cancer or the cancer treatment has interfered with your ability to live independently?

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
did not interfere at all extremely interfered with it

Appendix E
Centrality of Events Scale (CES)
 Berntsen & Rubin (2006)

Instructions: In answering the following questions, please keep *your cancer diagnosis* in mind and answer the questions in reference to that event.

		Totally Disagree	Disagree	Neutral	Agree	Totally Agree
1.	This event has become a reference point for the way I understand new experiences	1	2	3	4	5
2.	I automatically see connections and similarities between this event and experiences in my present life	1	2	3	4	5
3.	I feel that this event has become a part of my identity	1	2	3	4	5
4.	This event can be seen as a symbol or mark of important themes in my life	1	2	3	4	5
5.	This event is making my life different from the life of most other people	1	2	3	4	5
6.	This event has become a reference point for the way I understand myself and the world	1	2	3	4	5
7.	I believe that people who haven't experienced this type of event think differently than I do	1	2	3	4	5
8.	This event tells a lot about who I am	1	2	3	4	5
9.	I often see connections and similarities between this event and my current relationships with other people	1	2	3	4	5
10.	I feel that this event has become a central part of my life story	1	2	3	4	5
11.	I believe that people who haven't experienced this type of event have a different way of looking upon themselves than I have	1	2	3	4	5

12.	This event has colored the way I think and feel about other experiences	1	2	3	4	5
13.	This event has become a reference point for the way I look upon my future	1	2	3	4	5
14.	If I were to weave a carpet of my life, this event would be in the middle with threads going out to many other experiences	1	2	3	4	5
15.	My life story can be divided into two main chapters: one is before and one is after this event happened	1	2	3	4	5
16.	This event permanently changed my life	1	2	3	4	5
17.	I often think about the effects this event will have on my future	1	2	3	4	5
18.	This event was a turning point in my life	1	2	3	4	5
19.	If this event had not happened to me, I would be a different person today	1	2	3	4	5
20.	When I reflect upon my future, I often think back to this event	1	2	3	4	5

Appendix F
Self-Perception Profile for Adolescents
What I Am Like: Scoring Key
Harter (2012)

	Really True for me	Sort of True for me			Sort of True for me	Really True for me	
Sample Sentence							
a.	<input type="checkbox"/>	<input type="checkbox"/>	Some teenagers like to go to movies in their spare time	BUT	Other teenagers would rather go to sports events	<input type="checkbox"/>	<input type="checkbox"/>
1.	4	3	Some teenagers feel that they are just as smart as others their age	BUT	Other teenagers aren't so sure and wonder if they are as smart	2	1
2.	1	2	Some teenagers find it hard to make friends	BUT	Other teenagers find it pretty easy to make friends	3	4
3.	4	3	Some teenagers do very well at all kinds of sports	BUT	Other teenagers <i>don't</i> feel that they are very good when it comes to sports	2	1
4.	1	2	Some teenagers are <i>not</i> happy with the way they look	BUT	Other teenagers <i>are</i> happy with the way they look	3	4
5.	4	3	Some teenagers feel that they are ready to do well at a part-time job	BUT	Other teenagers feel that they are not quite ready to handle a part-time job	2	1
6.	4	3	Some teenagers feel that if they are romantically interested in someone, that person will like them back	BUT	Other teenagers worry that when they like someone romantically, that person <i>won't</i> like them back	2	1
7.	4	3	Some teenagers usually do the right thing	BUT	Other teenagers often don't do what they know is right	2	1
8.	4	3	Some teenagers are able to make really close friends	BUT	Other teenagers find it hard to make really close friends	2	1
9.	1	2	Some teenagers are often disappointed with themselves	BUT	Other teenagers are pretty pleased with themselves	3	4

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
10.	1	2	Some teenagers are pretty slow in finishing their school work	BUT	Other teenagers can do their school work quickly	3 4
11.	4	3	Some teenagers know how to make classmates like them	BUT	Other teenagers don't know how to make classmates like them	2 1
12.	4	3	Some teenagers think they could do well at just about any new athletic activity	BUT	Other teenagers are afraid they might not do well at a new athletic activity	2 1
13.	1	2	Some teenagers wish their body was different	BUT	Other teenagers like their body the way it is	3 4
14.	1	2	Some teenagers feel that they <i>don't</i> have enough skills to do well at a job	BUT	Other teenagers feel that they <i>do</i> have enough skills to do a job well	3 4
15.	1	2	Some teenagers are <i>not</i> dating the people they are really attracted to	BUT	Other teenagers <i>are</i> dating those people they are attracted to	3 4
16.	1	2	Some teenagers often get in trouble because of things they do	BUT	Other teenagers usually <i>don't</i> do things that get them in trouble	3 4
17.	1	2	Some teenagers <i>don't</i> know how to find a close friend with whom they can share secrets	BUT	Other teenagers <i>do</i> know how to find a close friend with whom they can share secrets	3 4
18.	1	2	Some teenagers don't like the way they are leading their life	BUT	Other teenagers do like the way they are leading their life	3 4
19.	4	3	Some teenagers do very well at their classwork	BUT	Other teenagers <i>don't</i> do very well at their classwork	2 1
20.	1	2	Some teenagers don't have the social skills to make friends	BUT	Other teenagers do have the social skills to make friends	3 4
21.	4	3	Some teenagers feel that they are better than others their age at sports	BUT	Other teenagers don't feel they can play as well	2 1
22.	1	2	Some teenagers wish their physical appearance was different	BUT	Other teenagers like their physical appearance the way it is	3 4

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
23.	4	3	Some teenagers feel they are old enough to get and keep a paying job	BUT	Other teenagers do not feel that they are old enough, yet, to really handle a job well	2 1
24.	4	3	Some teenagers feel that people their age will be romantically attracted to them	BUT	Other teenagers worry about whether people their age will be attracted to them	2 1
25.	4	3	Some teenagers feel really good about the way they act	BUT	Other teenagers <i>don't</i> feel that good about the way they often act	2 1
26.	4	3	Some teenagers <i>do</i> know what it takes to develop a close friendship with a peer	BUT	Other teenagers <i>don't</i> know what to do to form a close friendship with a peer	2 1
27.	4	3	Some teenagers are happy with themselves most of the time	BUT	Other teenagers are often not happy with themselves	2 1
28.	1	2	Some teenagers have trouble figuring out the answers in school	BUT	Other teenagers almost always can figure out the answers	3 4
29.	4	3	Some teenagers understand how to get peers to accept them	BUT	Other teenagers don't understand how to get peers to accept them	2 1
30.	1	2	Some teenagers don't do well at new outdoor games	BUT	Other teenagers are good at new games right away	3 4
31.	4	3	Some teenagers think that they are good looking	BUT	Other teenagers think that they are not very good looking	2 1
32.	1	2	Some teenagers feel like they could do better at work they do for pay	BUT	Other teenagers feel that they are doing really well at work they do for pay	3 4
33.	4	3	Some teenagers feel that they are fun and interesting on a date	BUT	Other teenagers wonder about how fun and interesting they are on a date	2 1
34.	1	2	Some teenagers do things they know they shouldn't do	BUT	Other teenagers hardly ever do things they know they shouldn't do	3 4

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
35.	1	2	Some teenagers find it hard to make friends they can really trust	BUT	Other teenagers <i>are</i> able to make close friends they can really trust	3	4
36.	4	3	Some teenagers like the kind of person they are	BUT	Other teenagers often wish they were someone else	2	1
37.	4	3	Some teenagers feel that they are pretty intelligent	BUT	Other teenagers question whether they are intelligent	2	1
38.	4	3	Some teenagers know how to become popular	BUT	Other teenagers do not know how to become popular	2	1
39.	1	2	Some teenagers do not feel that they are very athletic	BUT	Other teenagers feel that they <i>are</i> very athletic	3	4
40.	4	3	Some teenagers really like their looks	BUT	Other teenagers wish they looked different	2	1
41.	4	3	Some teenagers feel that they are really able to handle the work on a paying job	BUT	Other teenagers wonder if they are really doing as good a job at work as they should be doing	2	1
42.	1	2	Some teenagers usually <i>don't</i> go out with people they would really like to date	BUT	Other teenagers <i>do</i> go out with people they really want to date	3	4
43.	4	3	Some teenagers usually act the way they know they are supposed to	BUT	Other teenagers often don't act the way they are supposed to	2	1
44.	1	2	Some teenagers <i>don't</i> understand what they should do to have a friend close enough to share personal thoughts with	BUT	Other teenagers <i>do</i> understand what to do to have a close friend with whom they can share personal thoughts	3	4
45.	4	3	Some teenagers are very happy being the way they are	BUT	Other teenagers often wish they were different	2	1

Susan Harter, Ph.D., University of Denver, 2012

Appendix G
Self-Perception Profile for Adolescents
What I Am Like: Scoring Key
Harter (2016)

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
1. <i>Intell</i>	1	2	Some young adults do <i>not</i> feel mentally able to cope with the situations they now must face	BUT	Other young adults do feel mentally capable of coping with their new life situations	3 4
2. <i>Job</i>	4	3	Some young adults believe that they have found a rewarding job where they can develop their talents	BUT	Other young adults have <i>not</i> found such a rewarding job opportunity	2 1
3. <i>Athl</i>	1	2	Some young adults, since high school, have <i>not</i> been able to find outlets for their athletic energies	BUT	Other young adults have found rewarding avenues where they can demonstrate their athletic skills	3 4
4. <i>App</i>	4	3	Some young adults currently like their physical appearance; it is appropriate for their age and social situation	BUT	Other young adults do <i>not</i> like their current physical appearance	2 1
5. <i>Peer</i>	4	3	Some young adults have been able to establish new and meaningful social relationships since leaving high school	BUT	Other young adults have found it difficult to establish new and meaningful relationships	2 1
6. <i>IntRel</i>	4	3	Some young adults feel that they are developing the capacity to engage in relationships that are more intimate than casual dating	BUT	Other young adults feel that they have yet to experience this capacity	2 1

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
7. PRel	4	3	Some young adults feel that they are able to maintain a close relationship with their parents while at the same time beginning to be their “own person”	BUT	Other young adults do <i>not</i> seem to be able to do both	2 1
8. Moral	4	3	Some young adults feel that their moral principles are becoming clearer and more crystallized	BUT	Other young adults are struggling to establish their own clear moral standards	2 1
9. Hum	4	3	Some young adults are able to laugh at some ironies of life that now confront them	BUT	Other young adults are more cynical and less able to laugh about their unexpected current life experiences	2 1
10. Daily	4	3	In the face of current living arrangements, some young adults feel that they are managing pretty well	BUT	Other young adults are having difficulty adjusting to current living arrangements	2 1
11. Optim	4	3	Some young adults are optimistic about creating and achieving their future goals	BUT	Other young adults are more pessimistic about whether they can create and achieve future goals	2 1
12. TFSelf	4	3	Some young adults feel that they are able to be their <i>true</i> selves in most current situations	BUT	Other young adults find that they put on a false self much of the time	2 1
13. SE	4	3	Some young adults like the kind of person they are becoming	BUT	Other young adults do <i>not</i> like the kind of person they seem to be, they wish they could be different	2 1
14. Intell	4	3	Some young adults feel intellectually equipped to meet the problem-solving demands of this period of their life	BUT	Other young adults do <i>not</i> feel intellectually equipped	2 1
15. Job	1	2	Some young adults do <i>not</i> feel that they are moving in the right direction in terms of selecting a promising occupation	BUT	Other young adults <i>do</i> feel that that they are moving in the right occupational direction	3 4
16. Athl	4	3	Some young adults have been able to find opportunities to use their physical abilities	BUT	Other young adults have <i>not</i> been able to find such opportunities	2 1
17. App	4	3	Some young adults like the way they look, although their standards have changed since high school	BUT	Other young adults do <i>not</i> like the way they look in the face of changing standards	2 1

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
18. Peer	1	2	Some young adults have <i>not</i> made friends in their current work or educational environment	BUT	Other young adults <i>have</i> been able to make satisfying friendships at their work or in their educational environment	3 4
19. IntRel	1	2	Some young adults question whether they will have the ability to move into a committed relationship	BUT	Other young adults <i>do</i> feel that they have the ability to commit to a serious relationship, eventually	3 4
20. PRel	4	3	Some young adults are learning to balance their developing independence from parents with different and more mature types of dependence upon parents for support	BUT	Other young adults have difficulty achieving this balance between independence from, and dependence upon, parents	2 1
21. Moral	1	2	Some young adults are having difficulty developing their own independent ethical guidelines	BUT	Other young adults are more successful at creating personal ethical guidelines, separate from those imposed by others	3 4
22. Hum	1	2	Some young adults find it difficult to find humor in uncomfortable situations that face them at this point in their lives	BUT	Other young adults can maintain a sense of humor in the face of new and sometimes awkward situations	3 4
23. Daily	1	2	Some young adults are facing challenges coping with the need to make their own day-to-day decisions	BUT	Other young adults seem to be able to cope with their new decision-making responsibilities	3 4
24. Optim	1	2	Some young adults feel rather hopeless about whether they can fulfill their personal aspirations	BUT	Other young adults are hopeful that they will fulfill their personal aspirations	3 4
25. TFSelf	1	2	Some young adults feel that currently they need to act phony in order to cope socially	BUT	Other young adults do <i>not</i> have to be phony in order to cope pretty well in social situations	3 4
26. SE	1	2	Some young adults do <i>not</i> feel good about themselves overall; they experience low self-esteem	BUT	Other young adults do feel good about themselves; they have high self-esteem	3 4
27. Intell	1	2	Some young adults now question whether they are very intelligent	BUT	Other young adults do feel that they are quite intelligent	3 4

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
28. Job	4	3	In exploring job possibilities, some young adults feel confident that they will do well at the work that they have chosen	BUT	Other young adults do <i>not</i> feel confident about their abilities at their current choice of jobs	2 1
29. Athl	1	2	Some young adults have <i>not</i> found ways to get the physical exercise they need	BUT	Other young adults have been successful at finding ways to get needed physical exercise	3 4
30. App	1	2	Some young adults are currently unhappy with their body and weight, wishing they were different	BUT	Other young adults <i>are</i> happy with their body and weight right now	3 4
31. Peer	1	2	Some young adults feel that they are <i>not</i> accepted by their peers given their current life situation	BUT	Other young adults currently feel that there are peers who do accept them	3 4
32. IntRel	4	3	Some young adults feel that a genuine, deep love relationship may be possible	BUT	Other young adults question whether this will be possible	2 1
33. PRel	1	2	Some young adults are having difficulty negotiating their changing relationship with their parents	BUT	Other young adults are negotiating these changes pretty successfully	3 4
34. Moral	1	2	Some young adults are still searching for a solid sense of their own core personal values	BUT	Other young adults seem to be developing personal values that they feel are very solid	3 4
35. Hum	4	3	Some young adults don't take themselves too seriously and can laugh off situations that might be a cause for embarrassment	BUT	Other young adults find it hard to see the humor in situations that might be personally embarrassing	2 1
36. Daily	1	2	Some young adults struggle with the need to structure their time and meet the current obligations in their everyday life	BUT	Other young adults are able to handle these demands pretty successfully	3 4
37. Optim	4	3	Some young adults display optimism about creating a rewarding future life	BUT	Other young adults experience pessimism about the life they face ahead of them	2 1
38. TFSelf	4	3	Some young adults are able to be their true selves, their real selves inside	BUT	Other young adults struggle to act like the self they really are inside	2 1
39. SE	4	3	Some young adults are typically pleased with themselves	BUT	Other young adults are often disappointed with themselves	2 1

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
40. <i>Intell</i>	4	3	Some young adults feel that they have the “smarts” to successfully compete with others at this point in their development	BUT	Other young adults feel that they lack the “smarts” to compete	2 1
41. <i>Job</i>	1	2	Some young adults do <i>not</i> feel competent at their current job because they have not clarified their employment goals	BUT	Other young adults <i>do</i> feel competent at the job they selected as their occupational goals have become clearer	3 4
42. <i>Athl</i>	4	3	Some young adults have been able to find sports partners or teams that allow them to perform at their highest level of play	BUT	Other young adults have been <i>unable</i> to find sports partners or teams that allow them to perform at their highest level	2 1
43. <i>App</i>	1	2	Some young adults do <i>not</i> feel that they are physically attractive, given their goals for how they want to look	BUT	Other young adults do feel satisfied that they are meeting their goals for attractiveness	3 4
44. <i>Peer</i>	4	3	Some young adults have been able to make new and supportive friends since leaving high school	BUT	Other young adults have had difficulty developing new and supportive friendships	2 1
45. <i>IntRel</i>	4	3	Some young adults have entertained the idea of moving into a serious and rewarding long-term intimate relationship as they mature	BUT	Other young adults have doubts about whether such an intimate relationship will ever be possible for them	2 1
46. <i>PRel</i>	1	2	Some young adults seem unable to establish their autonomy from their parents while retaining a sense of connectedness	BUT	Other young adults have found a way to combine autonomy from parents with a modified sense of connectedness to parents	3 4
47. <i>Moral</i>	4	3	Some young adults are aware that knowing right from wrong requires new moral standards	BUT	Other young adults are <i>not</i> so concerned with issues of morality at this point in their development	2 1
48. <i>Hum</i>	4	3	Some young adults can laugh at themselves when things don’t always go as they personally planned	BUT	Other young adults have a hard time finding any humor at their expense, when things don’t go as planned	2 1
49. <i>Daily</i>	4	3	Some young adults seem to be able to successfully manage the current requirements of daily life (for example, household chores, meals, expenses, getting to work or classes on time)	BUT	Other young adults are having difficulty managing the current requirements of daily life	2 1

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
50. Optim	1	2	Some young adults often feel hopeless, fearing that they cannot create a rewarding future life	BUT	Other young adults feel hopeful about creating a rewarding future life	3 4
51. TFSelf	1	2	Some young adults feel compelled to adopt a false self in order to survive socially at this point in their lives	BUT	Other young adults are able to rely on their true selves in order to both survive and succeed socially	3 4
52. SE	1	2	Some young adults are unhappy with how they are currently leading their lives	BUT	Other young adults are pretty pleased with the way they are presently leading their lives	3 4

Appendix H

Table 3

Descriptive Statistics

	Demographic Factors										
	Total N = 12	Gender		Age Category		Engagement Habits		Treatment Status		Months since Dx	
		F N = 7	M N = 5	Adolescent N = 7	Young Adult N = 5	Low N = 7	High N = 5	On N = 9	Off N = 3	≤ 5mo N = 6	≥ 6mo N = 6
Social Support											
<i>MSPSS</i>	5.62 (.73)	5.67 (.84)	5.55 (.63)	5.61 (.80)	5.63 (.71)	5.80 (.80)	5.34 (.60)	5.74 (.74)	5.25 (.68)	5.58 (.88)	5.65 (.63)
Fam	5.58 (1.42)	5.82 (1.73)	5.25 (.92)	5.54 (.93)	5.65 (2.07)	6.07 (1.02)	4.90 (1.74)	5.83 (1.00)	4.83 (2.45)	5.79 (1.13)	5.38 (1.75)
Fri	5.75 (1.17)	5.93 (1.36)	5.50 (.92)	5.36 (1.40)	6.30 (.41)	5.39 (1.38)	6.25 (.59)	5.47 (1.23)	6.58 (.14)	5.17 (1.45)	6.33 (.30)
SO	5.52 (1.56)	5.25 (1.99)	5.90 (.63)	5.93 (.73)	4.95 (2.27)	5.93 (.53)	4.95 (2.35)	5.92 (.64)	4.33 (2.98)	5.79 (.70)	5.25 (2.16)
<i>OSSS</i>	82.83 (40.37)	81.71 (53.02)	84.40 (16.13)	79.00 (32.20)	88.20 (53.53)	75.57 (30.64)	93.00 (53.40)	78.00 (28.20)	97.33 (73.22)	77.33 (35.26)	88.33 (47.64)
Esteem/Emotional	27.33 (10.65)	26.57 (13.14)	28.40 (7.13)	27.43 (9.57)	27.20 (13.22)	26.71 (9.57)	28.20 (13.16)	27.00 (8.37)	28.33 (18.50)	26.50 (10.31)	28.17 (11.91)
Social Companionship	21.25 (13.65)	20.43 (16.45)	22.40 (10.16)	21.57 (13.43)	20.80 (15.53)	18.57 (11.01)	25.00 (17.32)	20.56 (12.06)	23.33 (20.82)	20.33 (14.84)	22.17 (13.69)
Informational	20.50 (11.14)	21.29 (14.37)	19.40 (5.37)	19.00 (8.70)	22.60 (14.77)	18.14 (8.07)	23.80 (14.84)	18.56 (7.65)	26.33 (19.50)	19.17 (9.09)	21.83 (13.64)
Instrumental	13.75 (9.22)	13.43 (11.79)	14.20 (4.97)	11.00 (4.83)	17.60 (12.92)	12.14 (6.26)	16.00 (12.81)	11.89 (5.44)	19.33 (16.92)	11.33 (5.05)	16.17 (12.14)
Cancer Impact											
Centrality of Events	4.06 (.62)	4.29 (.57)	3.73 (.58)	3.94 (.61)	4.22 (.67)	3.93 (.52)	4.24 (.77)	3.87 (.57)	4.63 (.42)	3.74 (.49)	4.38 (.61)
Young Adult Cancer Impact	7.42 (3.32)	8.71 (1.38)	5.60 (4.51)	7.71 (3.40)	7.00 (3.54)	7.86 (3.33)	6.80 (3.56)	6.89 (3.69)	9.00 (1.00)	7.50 (3.51)	7.33 (3.45)
Self-Perception											
SPPA											
N = 7											
Physical Appearance	2.63 (.80)	2.67 (1.14)	2.60 (.63)			2.60 (.95)	2.70 (.42)			2.60 (.95)	2.70 (.42)
Close Friendships	2.77 (.90)	2.67 (1.53)	2.85 (.19)			2.76 (1.09)	2.80 (.28)			2.48 (.84)	3.50 (.71)
Social Competence	3.06 (.86)	2.80 (1.39)	3.25 (.30)			3.00 (1.04)	3.20 (.28)			2.88 (.99)	3.50 (.14)
Global Self-Worth	2.97 (.56)	2.80 (.87)	3.10 (.26)			2.92 (.67)	3.10 (.14)			2.76 (.48)	3.50 (.42)

SPPEA*N* = 5

<i>Physical Appearance</i>	2.40 (.88)	2.19 (.85)	3.25 (*)	2.88 (.53)	2.08 (1.01)	2.87 (.53)	2.08 (1.01)	2.5 (*)	2.38 (1.01)
<i>Peer/Social</i>	2.95 (.93)	3.00 (1.06)	2.75 (*)	3.25 (.71)	2.75 (1.15)	3.25 (.71)	2.75 (1.15)	3.75 (*)	2.75 (.94)
<i>Global Self-Esteem</i>	2.30 (.65)	2.25 (.74)	2.5 (*)	2.75 (.35)	2.00 (.66)	2.75 (.35)	2.00 (.66)	3.00 (*)	2.13 (.60)

Note. *No standard deviation reported due to only having one participant in this demographic category.