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Identity Development in Adolescent and Young Adult Cancer Survivors

by

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Abstract

A key milestone in adolescence is the development of one's identity. This process can be interrupted by traumatic events, including a cancer diagnosis and treatment. The current study investigated identity development among adolescent and young adult (AYA) cancer survivors (n=153). We also examined the relationship between identity development with body image, self-esteem and self-perception. Participants were between the ages of 15 and 26 and were diagnosed with cancer between the ages of 14 and 21. All participants completed multiple questionnaires, including the Extended Objective Measure of Ego Identity Status (EOM-EIS-II), the Self-Perception Profile for Adolescents (SPPA), Rosenberg's Self-Esteem Scale, and the Body Image Instrument (BII). Most adolescent and young adult cancer survivors were found to be in identity moratorium (individuals in a crisis period, actively self-exploring possible selves). Multiple one-way ANOVAs suggested that self-esteem and self-perception had a relationship with the identity status. These results suggest that AYA survivors' sense of self (how they perceive themselves, and how much they like themselves) are associated with their identity status. AYA survivors with more positive self-perception and self-esteem will be more likely to successfully reach identity achievement and have an overall more positive sense of self.

In the United States, over 70,000 individuals between the ages of 15 and 39 receive a cancer diagnosis annually (Chou & Moskowitz, 2016). While cancer remains the leading cause of disease-related death in adolescents and young adults (AYAs), 73-82% will survive at least five years post diagnosis (Clinton-McHarg, et al., 2010). In fact, the overall number of cancer survivors of all ages increased to more than 14 million in the United States because of improvements in basic and clinical research, advancing multi-institutional clinical trials through the cooperative group structure, introducing new agents and improving the supportive care of diagnosed individuals (Baassiri & Mulrooney, 2016). Technological and medical advancements have led to better preventative care, greater chances for early detection and more powerful cancer treatments.

The survival rates of the adolescent and young adult population have not increased as much as other age groups, but significant improvements have been made and an increasing number of AYA cancer patients are becoming long-term cancer survivors (Baassiri & Mulrooney, 2016). With the increase in survival rate, there are more survivors that are living longer with the psychosocial sequelae of their diagnosis and the treatment (Clinton-McHard, et al., 2010). This population has a unique cancer experience that is different from any other age group, showing that this group has greater psychosocial struggles, and has been studied less than older and younger age groups despite the need for a focus on adolescent and young adult oncology (Bleyer, et al., 2017).

Some of the most common cancer diagnoses in adolescents and young adults include brain and central nervous system tumors, breast cancer, cervical cancer, colorectal cancer, germ cell tumors, leukemia, liver cancer, lymphoma, melanoma, sarcomas, testicular cancer and thyroid cancer (National Cancer Institute, 2018). Between 1975 and 2012, there have also been

significant reductions in the incidence of some cancers that affect adolescents and young adults (AYA), such as uterine cervix cancer because of the development of the pap smear and HPV immunizations (Bleyer, et al., 2017). While most adolescent and young adults are in relatively good health, there are estimated to be more than 400,000 survivors of childhood, adolescent and young adult cancer in the United States today that face unique challenges due to the long-term effects of treatments and the increased likelihood of subsequent chronic illnesses (Prasad, et al., 2015).

The number of life-years that are affected by cancer is the greatest in the AYA population than any other age group, but little is known about the long-term effects of cancer and how this affects psychosocial development (Bleyer, et al., 2017). Many survivors face late effects, which are defined as health problems that can occur months or years after the initial cancer diagnosis or completion of treatment and can include physical, mental and social problems and second cancers (National Cancer Institute, 2018). In fact, about two-thirds of AYA cancer survivors face at least one chronic health condition that can include mental and cognitive problems as well as physical problems (Prasad, et al., 2015). More than 40% of AYA survivors show neurocognitive dysfunction with higher rates of processing speed, attention, memory and executive function (Prasad, et al., 2015). These late effects can have a significant impact on how survivors adapt to typical developmental tasks, such as their identity formation and autonomy from their family. Previous research suggests that cancer in adolescents and young adults can disrupt not only the physical growth process that is necessary for adulthood but also the psychosocial growth necessary to become an autonomous adult.

There are many developmental tasks that adolescents and young adults undergo as they transition to adulthood. Adolescence is the transition from being a child that is dependent on

parents and/or guardians to an independent, self-reliant and autonomous adult (Quas, 2014). This transition is one of the most influential periods of human development, being extremely dynamic and broad (Quas, 2014). In simpler terms, adolescence is the period of time that marks the transition from childhood to adulthood. This usually occurs between the ages of 12 and 18 years old, and corresponds to the beginning of puberty (Jaworska & MacQueen, 2015). Puberty is defined as the biological process driven by increases in adrenal and gonadal hormones, that includes the development of secondary sex characteristics and changes in body fat and muscle (Jaworska & MacQueen, 2015). During this time there is an increase in risk-taking behaviors and emotional reactivity that coincides with social changes, such as spending more time with peers than family. Behavioral changes during adolescents are influenced by internal factors, (e.g. puberty) and external factors, (e.g. environment), that elicit and reinforce behaviors (Jaworska & MacQueen, 2015).

As a child begins to develop into adolescence there are dramatic changes occurring biologically, behaviorally, and socially such as physical growth, body changes, sexual maturation, increased social anxieties, increased self-awareness and beginning of romantic interests (Forbes & Dahl, 2010). During puberty the development of brain structures and brain function continues, which includes an increase in cognitive control and executive functions (Forbes & Dahl, 2010). The greatest amount of physical development throughout the lifespan besides infancy occurs during adolescence (Markey, 2010). The beginning of puberty and the speed of its progression varies considerably between individuals, both within and between genders (Forbes & Dahl, 2010). Previous research suggests that pubertal maturation is associated with emotional and motivational changes that may have an influence on behavioral tendencies (Forbes & Dahl, 2010).

Puberty is one aspect of the many critical experiences that adolescents have during development and is related to other critical developmental experiences such as family, peer and romantic relationships, identity, and body image (Markey, 2010). How an individual perceives themselves throughout these experiences can have a major impact on the successful development of identity and the self. Specifically, perception of physical appearance influences an individual's personal sense of self because of the dramatic bodily changes that they need to adapt to and make sense of (Markey, 2010). Global self-esteem can be used as a construct for better understanding human behavior and different feeling states, while self-esteem refers to how much a person likes or dislikes themselves (Frost & McKelvie, 2004). There are a multitude of different changes occurring simultaneously during adolescence physically, emotionally and socially. Some of the vital characteristics of developmental change occur with age and not puberty so it is important to distinguish these differences to better understand what aspects of development are linked to puberty and what aspects are linked to other factors, such as social experiences (Forbes & Dahl, 2010). Adolescence is defined by a combination of many characteristics, making the disentanglement of the multitude of factors an important challenge.

Adolescence has recently expanded to include young adulthood, up to the ages of 25 years old because of the delayed development into adult roles associated with social and personal responsibilities (Jaworska & MacQueen, 2015). People are more likely to continue education post high school, begin jobs later, start families, buy houses/property, etc. later today than they used to leading to a delay in autonomy. During the beginning of adolescence and young adulthood, there is rapid development of neurocognitive functions that are related to the maturation of one's brain (Prasad, et al., 2015). This period happens during a developmental phase when certain behaviors are established and instilled. The brain continues to grow

throughout adolescence and into young adulthood with accelerated development of higher-order skills such as executive functions, so executive dysfunction may not be apparent until adulthood when individuals are expected to use advanced planning and reasoning abilities as independent people (Prasad, et al., 2015). Previous brain injury research demonstrates that injury during adolescence can result in executive dysfunction that is not demonstrated in individuals with injury during younger childhood, suggesting the vulnerability of the brain during adolescence when compared to younger children and older adults (Prasad, et al., 2015). This may suggest a similar impact on AYA cancer survivors, with powerful treatments being administered during a time of such physical vulnerability.

Adolescence and young adulthood are not only times of physical vulnerability, but psychological vulnerability as well. Adolescence is a critical time of a multitude of biological, cognitive and social changes, which introduces instability into their lives (Hatano, Sugimuyra & Schwartz, 2018). One of the most vital developmental tasks of adolescence is forming their own certain identity independent from that of their parents (Becht, et al., 2016). Typically, adolescents alternate between their families and their peers with increased importance on their friends. During this time families reorganize boundaries that allow for flexible movement within the family system, allowing for identity exploration and autonomy (Madan-Swain, et al., 2000). If certain identity cannot be obtained, it is not uncommon for these individuals to face identity foreclosure. This is when individuals haven't had the ability to question alternative points of view but have made commitments to a specific position that they will defend (Madan-Swain, et al., 2000). The positions are typically that of their parents, without any self-exploration of the point of view. The four main identity statuses include identity diffusion, identity foreclosure, identity moratorium and identity achievement. When an individual has gone through a process of

considering alternate selves and made a decision on their own terms, they have obtained identity achievement (Marica, 1966). People that have a complete lack of commitment to any certain self and are not in the process of considering alternate selves are in identity diffusion (Marica, 1966). Individuals in identity moratorium are in the middle of a crisis period but have yet to fully commit to a certain self (Marcia, 1966).

Identity formation is an important development task that is a key milestone for adolescents and young adults. During this period of identity formation AYA's typically develop a sense of purpose and establish future life goals (Sansom-Daly, et al., 2018). Identity formation is an individuation process where they learn to become autonomous without becoming completely disconnected from their families (Madan-Swain, et al., 2000). Adolescents do not begin this process with a blank slate, because they enter this period with a commitment to certain identity domains and ideologies that are based on the views and beliefs of the values and norms of their parents or guardians (Becht, et al., 2016).

The process of identity synthesis vs role confusion begins when AYAs challenge these commitments and attempt to form their unique identities with their own values, morals, and norms. It is important and necessary to experience identity uncertainty in this process of experimenting and "trying on identities" in order to eventually successfully consolidate a certain identity (Becht, et al., 2016). This process takes place on a daily basis, and it is assumed that these short-term identity processes will result in the resolution of long-term identity development (Becht, et al., 2016). This process continues into young adulthood.

Curiosity is an important part of identity development in adolescents and young adults because when individuals experience the developmental crises that come with exploring oneself,

it leads to uncertainty and questions that stimulate heightened curiosity. It is this curiosity that drives learning and development forward (Erikson, 1980). The two ways that curiosity is expressed is as a desire to reduce unpleasant feelings of being deprived of new knowledge needed to solve problems or it is to increase pleasurable feelings with a positively motivated desire for new information (Robinson, Demetre & Litman, 2017). Curiosity will lead to exploratory behaviors and information-seeking behaviors despite how it is expressed, including self-exploration. A person that has intrapersonal curiosity will introspect about their past, their emotions and their own identity as a way to seek out new information about themselves (Robinson, Demetre & Litman, 2017).

During this period of adolescence and young adulthood, the importance of peers in their lives increase drastically due to puberty, social norms and the increase of personal autonomy. While parents still remain important figures in their lives, they spend more time with their peers and value their opinions more creating increasingly complex friendships (Jones, et al., 2014). The increase in time spent with peers exposes them to a variety of values, morals and beliefs that they may have never been exposed to before, leading to an increase in curiosity and introspection. Friendship provides an important context for exploration and commitment as well as a reciprocal responsibility which are all essential to the formation of identity (Jones, et al., 2014).

Becht, et al., defines identity as a self-organizing system that operates on a daily basis, with the daily levels of identity commitment reflecting the AYA's attempt to develop and maintain a stable identity tapping into the short-term aspects of certainty in the identity formation process (2016). The process of identity formation is different for each individual, and while it can be very stressful for many AYA, it does not necessarily mean that all AYA will experience

identity crisis during their transition to adulthood. A significant number of individuals show identity uncertainty throughout their adolescence and young adulthood, with decreasing strengths of their current identity commitments and their consideration of multiple identity alternatives (Becht, et al., 2016). Many AYAs encounter phases of unstable and changing identities throughout their identity experimentation, but individuals that experience more uncertainty on a daily basis may be at a greater risk for psychosocial adjustment problems (Becht, et al., 2016).

There have been multiple theories written about adolescent development, but one such prominent theory of development was proposed by Erik Erikson. Erikson's theory of psychosocial development describes the developmental function and individual differences in development, and balances the weight of genes and the environment. This includes different levels of the environment from cultural influences down to the influences of the immediate family (Dunkel & Harbke, 2017). There is a balance between change and stability that allows early influences to remain important but also allows for new crises to emerge as individuals get older so they can reevaluate their past achievements and failures (Dunkel & Harbke, 2017).

There are eight psychosocial stages that emerge in different periods throughout the lifespan. Within each stage, there are two opposing tendencies. When there is a successful integration between the two opposing tendencies an ego strength is developed which then contributes to the resolution of the developmental crisis at that stage (Knight, 2016). When there is successful resolution of one stage, the individual can then continue the developmental process. Stage 1 is trust vs mistrust, which says that responsiveness and sensitivity of caregivers are the primary director of the development of trust. A basic sense of trust is instilled and the psychosocial strength of hope is gained. Stage 2 is autonomy vs shame and doubt. If caregivers provided appropriately guided opportunities for a child to explore their world, a sense of

autonomy develops. The psychosocial strength gained is will power / self-control. Stage 3 is initiative vs guilt. In this stage goal-directed actions increase. Children who can successfully pursue goals develop a sense of purpose as opposed to feeling aimless. Caretakers can assist children in developing strength and purpose by helping them formulate and reach realistic goals. The psychosocial strength is purpose. Stage 4 is industry vs inferiority where children develop a sense of what talents they possess. The honing of these skills results in a sense of industry. The psychosocial strength is competence. Stage 5 is identity vs role confusion. In this stage adolescents are faced with “who am I?” questions and positive resolution is when a sense of self-continuity is achieved. The psychosocial strength is fidelity, and this is gained when an adolescent is able to form their identity. When some sense of self-understanding is gained, a person can truly begin knowing others. Stage 6 is intimacy vs isolation which represents the ability to share with and commit to another, usually in the form of romantic relationships. The psychosocial strength is love. Stage 7 is generativity vs stagnation and this happens in middle adulthood. Individuals work towards influencing future generations. The psychosocial strength is care. The final stage, stage 8 is integrity vs despair. Life review is initiated, where old age individuals must look back on their lives with a sense of satisfaction or regret. The final psychosocial strength is wisdom (Dunkel & Harbke, 2017).

Each of these stages should not be viewed as categories, but rather a continuum in which the resolution of the previous stage is necessary for the next stage to develop successfully (Knight, 2016). To achieve the greatest possible psychological health there must be a balanced ratio between the two opposing tendencies. Identity formation is Erikson’s fifth stage of psychosocial development, and this stage is dependent upon the successful resolution of stages 1 through 4. This then in turn suggests that the formation of identity is extremely dependent upon

parents, siblings and society because of their importance in the preceding stages (Jones, et al., 2014). When an individual encounters an unstable period and they do not feel like they are able to appropriately cope with this instability they can experience a crisis and begin to intensely question their own lifestyle, beliefs and understandings (Robinson, Demetre & Litman, 2017). Erikson considered identity crisis a normal part of the psychosocial development of individuals attempting to form a stable sense of self (Becht, et al., 2016).

The three components of Erikson's theory on identity include synthesis, confusion and consolidation whereas synthesis represents a coherent and consistent sense of self, confusion represents a fragmented and unpredictable sense of self, and consolidation represents the interplay between confusion and synthesis (Hatano, Sugimura & Schwartz, 2018). Synthesis and confusion are both necessary for the successful development of certain identity, but it is important for there to be more synthesis than confusion. While finding the appropriate balance between identity synthesis and identity confusion can be a difficult developmental task for many adolescents, it can be especially stressful for AYA's dealing with the ramifications of a cancer diagnosis, treatment, and the resulting physical and psychological symptoms that many adolescents with good health do not have to deal with.

Previous research suggests that chronic illness can negatively influence the formation of identity (Hauser, et al., 1992). This process is an already difficult psychosocial task, and the added stress and anxieties that come with a cancer diagnosis are likely to restrict higher levels of identity formation (Tramontana & Hooper, 1997). Adolescent and young adults that have cancer can have many of their developmental milestones interrupted such as separating from their parents, forming social and romantic relationships, completing education and/or training, beginning careers, and starting families (Chou & Moskowitz, 2016). They may deal with identity

foreclosure because of limited cognitive and physical functioning or other symptoms that come along with cancer treatments. This can be used as a coping mechanism to help deal with the stress of cancer and its treatment because they do not have to deal with the uncertainty of exploring future alternatives on top of the daily stressors the illness itself causes (Madan-Swain, 2000).

This age group is of particular importance because they experience cancer differently than younger children and older adults do because of the unique phase of life they are in at the time of diagnosis and throughout the intense treatments (Husson & Zabrack, 2017). They experience similar physical, psychological, social and spiritual concerns that cancer survivors of all ages experience but they have added concerns because of the critical developmental stage they are at (Clinton-McHard, et al., 2010). Because of the unique developmental phase, cancer research including all ages may not be generalized to the specific population appropriately. The adolescent and young adult years are extremely dynamic and challenging despite the addition of a severe chronic illness, so it is common for long-term survivors to experience extraordinary challenges to their quality of life that will affect them for the rest of their lives even if they are “cured” (Bleyer, et al., 2017).

When an individual is diagnosed with cancer during the critical time of adolescence or young adulthood it can disrupt the physical, psychological and social development that is necessary to transition into adulthood. Cancer treatments during this time may interfere with the separation from parents, autonomy from family and within social groups, social and educational activities, and maintaining privacy, specifically of their own bodies (Prasad, et al., 2015). When AYAs are compared to adult cancer survivors, they are more likely to report greater concern about being physically unable to have children, difficulty pursuing a career, fear of loss of health

insurance, greater financial instability, job discrimination and more family problems (Chou & Moskowitz, 2016). When survivors are diagnosed during adolescence, they are more likely to report significant emotional distress and neurocognitive dysfunction when compared to their healthy peers. They were less likely to continue education post high school, attain fulltime jobs, get married, or to live independently (Prasad, et al., 2015). This previous research suggests that the unique social-psychological challenges faced can greatly impact identity development, coping, distress and social relationships (Chou & Moskowitz, 2016).

How survivors adjust to their cancer experience can have lifelong implications for their quality of survival (Husson & Zabrack, 2017). It is extremely important to assess cancer impact in these individuals because of the increased vulnerability of stress during this time. They are experiencing a rare and unexpected event that can make it difficult to view their futures in a developmentally “normal” way and can influence how they adapt to their survivorship (Sansom-Daly, et al., 2018). A critical part of how individuals adjust to stressful life events include autobiographical thinking processes, or how one thinks about their past and their future (Sansom-Daly, et al., 2018). Autobiographical thinking processes can be especially critical for adolescents and young adults throughout their process of identity formation. Cancer can be considered a traumatic event and can alter personal beliefs about oneself and the world, which can have significant implications in how a person establishes their identity. For a person to positively adapt to a traumatic event in their lives it is critical to be able to process and integrate stressful events into meaningful life narratives (Sansom-Daly, et al., 2018). The individual sense of self and self-efficacy is determined by what personal memories they draw upon, so if negative cancer memories are drawn upon in relation to the self, they may struggle more with positive identity consolidation than an individual that draws upon the more positive cancer memories (Sansom-

Daly, et al., 2018). Non-specific memories include the overgeneralization of memories and has been linked to depression, complicated grief and posttraumatic stress disorder in cancer patients. Specific memories allow individuals to draw specific information from their memories and helps them picture future life events that are consistent with their goals and assist in their ability to problem solve future oriented problems. Cancer patients that have specific memories are more likely to integrate their illness experiences into their identity, be more autonomous and have a greater ability to self-manage (Sansom-Daly, et al., 2018).

The return to normal activities is usually determined by the end of cancer treatments where the individual is expected to integrate back into the typical developmental setting and begin to determine life goals and make meaningful choices (Choquette, Rennick & Lee, 2016). Little is known about the transition back into normal daily activities and how it affects the psychosocial development of adolescents and young adults that have completed cancer treatments. More specifically, little is known about what the life-long implications of a cancer diagnosis and treatments during the vulnerable years of adolescence and young adulthood are and how it affects the development and consolidation of certain identity.

Therefore, given the evidence suggesting the long-term impact cancer diagnosis and treatment has on the identity formation of adolescent and young adult cancer survivors, we have chosen to focus on body image, self-esteem, and sense of self and how they each relate to the development of one's identity in this specific population. The overall goals of this study were to examine identity status, body image, self esteem and self perception among AYA cancer survivors. We then explored the relationship of body image, self-esteem, and self-perception with identity. Our hypotheses included the following: a greater proportion of AYA survivors would be categorized as in identity foreclosure; survivors would have fairly poor body image but

that those with better body image would likely be categorized as in identity achievement; participants with higher self-esteem would have a greater likelihood of being in identity achievement; and participants with higher self-perception would be more likely be in identity achievement.

Methods

Procedure

This project was part of a larger study conducted at Memorial Sloan Kettering Cancer Center that investigated identity development in AYA cancer survivors who were diagnosed with cancer during adolescence and young adulthood. Potential participants were identified through the hospital's medical records database after it was approved by the Institutional Review Board at Memorial Sloan Kettering Cancer Center (Protocol #09-001). Eligibility criteria included: (1) current age between 15 and 25 years, (2) initial cancer diagnosis between ages 14 and 21, (3) at least 6 months post treatment, (4) able to provide consent if 18 years of age or older, or parental consent (and participant assent) if they were under 18 years of age, and (5) English-speaking. Participants were excluded if they had cognitive impairment identified by their primary physician as being severe enough to prevent them from providing consent or assent to complete the study.

Potential participants received a letter in the mail from the principal investigator that outlined the purpose of the study and invited them to participate. This included an informed consent document, a sample questionnaire, and a postage-paid envelope that the potential participant could return all of the completed documents. If they did not respond to the letter with the accompanying documents within two weeks, a research assistant contacted them by phone if

they were 18 or older, or their parents by phone for minors. The questionnaires were mostly administered by a trained research assistant over the phone, although online and paper surveys were utilized where participants were unavailable or unwilling to complete surveys by telephone.

Participants

A total of 382 AYA cancer survivors were determined to be eligible for the study out of the pool of 453 AYAs that were originally screened. Of these 382, the research team was able to contact 221 survivors, 68 of which declined to participate (71% participation rate). Reasons for refusal to participate in the study included: being not interested ($n = 22$), not comfortable ($n = 16$), too busy ($n = 15$), and privacy concerns ($n = 1$). The final sample for this study included a total of 153 AYA cancer survivors. Eighty-nine of the participants (58.2%) were male and sixty-four (41.8%) were female. They were between the ages of 16 and 26 ($M=21.8$, $SD=2.5$), and were initially diagnosed with cancer between the ages of 14 and 20 ($M=16.8$, $SD=1.9$). Cancer diagnoses included Thyroid (24.2%), Germ cell Cancer (20.9%), Hodgkins Lymphoma (19.6%), Non-Hodgkins Lymphoma (10.5%), Leukemia (7.2%), Sarcoma (5.2%), Carcinoma (3.9%), Lymphoma (3.9%), and other (4.6%). Most identified as White (91.5%), with a smaller number reporting that they were Black/African American (3.9%), American Indian or Alaskan Native (1.3%), Asian/Pacific Islander (1.3%), or Other (2%). See Table 1 for additional demographic and medical characteristics of the sample.

Measures

Extended Objective Measure of Ego Identity Status (EOM-EIS-II)

The EOM-EIS-II is a 64 item Likert scale (1=strongly disagree to 6=strongly agree), given to participants to classify them into an identity status group. Eight items are included in

each of the identity status subscales, with scores ranging from 1 to 48. The scores separate individuals as being in identity diffusion, identity foreclosure, identity moratorium or identity achievement. Individuals classified as being in identity diffusion on the EOM-EIS-II lack self-exploration and commitment, identity foreclosure is associated with commitment based on little or no self-exploration of alternatives, identity moratorium is characterized by exploration of alternatives but have yet to commit and identity achievement entails having made a commitment to choices based on self-exploration of other alternatives (Grace and Adams, 1984). Previous studies have demonstrated moderate internal consistency as well as convergent-discriminant and construct validity (Jones, Arkers, & White, 1994). Some items from the EOM-EIS-II include, “There are lots of different kinds of people. I’m still exploring the many possibilities to find the right kind of friends for me,” “I don’t give religion much thought and it doesn’t bother me one way or the other,” and “In finding an acceptable viewpoint to life itself, I find myself engaging in a lot of discussion with others and some self-exploration.”

Self-Perception Profile for Adolescents (SPPA)

The SPPA is a questionnaire that measures an individual’s perception of their competence and self-worth. This study administered 30 items from the SPPA and included 6 subscales (social acceptance, athletic competence, romantic appeal, close friendship, physical appearance and global self-worth). Items were scored from 1 to 4, with a score of 4 representing the most adequate self-judgement and a score of 1 representing the least adequate self-judgement (Harter, 2012). Participants were given two statements and were asked to check off a box stating that one of the statements is “really true for me,” or “sort of true for me.” The SPPA has demonstrated good construct validity as well as high internal consistency (Harter, 2012). Some items from the Self-Perception Profile for Adolescents are, “Some people find it hard to make

friends BUT for other people it's pretty easy," "Some people are able to make really close friends BUT other people find it hard to make really close friends," and "Some people are often disappointed with themselves BUT other people are pretty pleased with themselves."

Rosenberg's Self-Esteem Scale

Rosenberg's Self-Esteem Scale is a 10-item measure that asks items on a 4-point Likert scale that measures the self-esteem of individuals, from strongly agree to strongly disagree. Scores are added based on responses and the higher the score on the scale, the higher the self-esteem of the individual. Scores on the Rosenberg Self-Esteem Scale range from a minimum of 10, to a maximum of 40. The scale has been determined to indicate low self-esteem (scores 10-25), medium level of self-esteem (scores 26-29), and high level of self-esteem (scores 30-40; Garcia, et. al., 2018). Rosenberg's Self-Esteem Scale has good external validity, internal consistency and reliability in different cultures and languages (Garcia, et al., 2018). Some items from Rosenberg's Self-Esteem Scale include, "On the whole, I am satisfied with myself," "I feel that I'm a person of worth, at least on an equal plane with others," and "All in all, I am inclined to feel that I am a failure."

Body Image Instrument (BII)

The Body Image Instrument measures body image and sexual identity on a 28-item self-report questionnaire with items rated on a five-point Likert scale from strongly disagree to strongly agree. The five subscales included are general appearance (feelings about one's physical appearance), body competence (feelings about one's physical strength, stamina and coordination), other's reaction to appearance (one's perception of how others react to their appearance), value of appearance (the relative importance of appearance), and body parts

(feelings about body parts that are commonly affected by cancer treatments) (Kopel, et al., 1998). Some items were reverse scored, and higher scores indicated a stronger agreement with each statement, therefore also indicating a more positive body image. Scores ranged from 1-5, with 5 representing the most positive body image and 1 representing the most negative body image. The study investigating the BII assessment by Kopel and colleagues demonstrated adequate internal reliability and concurrent validity for the Body Image Instrument (Kopel, et al., 1998). Some items from the Body Image Instrument include, “I think I look good in a bathing suit,” “I am very satisfied with my weight,” and “I feel people avoid me because of the way I look.”

Results

Aim 1: To determine the proportion of AYA survivors in each identity category

One-hundred and thirty-three participants were categorized in one of the four identity status groups based on their responses to the EOM-EIS-II questionnaire. While it was hypothesized that the majority of AYA cancer survivors would be in identity foreclosure, only 16.5% (n=22) were identified as identity foreclosures. However, 38.3% (n=51) of participants were in identity moratorium, 33.1% (n=44) were in identity diffusion, and 12% (n=16) were in identity achievement. (See Table 2 and Figure 1). There were no significant differences found between identity status by participants’ age at study participation, age at cancer diagnosis or gender.

Aim 2: To determine survivors' body image and its relationship with identity

Body image was assessed with the Body Image Instrument, which examines how AYAs view their own bodies. The Body Image Instrument includes 5 subscales; others' reaction to appearance, body competence, general appearance, value of appearance and body parts. Mean scores of each subscale were moderate, indicating that AYA cancer survivors did not have low body image, contrary to the study hypothesis. The means and standard deviations by subscale can be found in Table 3. There were no significance differences found between any body image subscale by participants' age at study participation, age at cancer diagnosis or gender. We then examined whether there were differences in body image by identity status by conducting a one-way analysis of variance (ANOVA). Means for each subscale were relatively similar across identity status. Means, standard deviations and p-values for each body image subscale by identity status groups are available in Table 3. There were no significant differences by identity status group with respect to body image, despite our hypothesis that those with higher body image would be more likely to be in Identity Achievement (see Table 3).

Aim 3: To describe survivors' self esteem and its relationship with identity

Self-esteem was assessed using Rosenberg's Self-Esteem Scale to examine the overall self-worth of the AYA participants ($M= 23.2$, $SD=5.2$), indicating a fairly low level of self esteem. There were no significant differences found on self-esteem by participants' age at study participation, age at cancer diagnosis or gender. We then examined self-esteem scores by identity status group. Descriptive statistics for Rosenberg's Self-Esteem scores by identity status are available in Table 3. We conducted a one-way ANOVA to examine self-esteem differences by identity status and found the effect of identity status was significant on self-esteem, $F(1,153) =$

3.96, $p < .01$. Post hoc analyses using Tukey post hoc criterion for significance indicated that the average self-esteem was significantly lower among identity diffusion ($M=21.39$, $SD=5.39$) than among those in identity achievement ($M=25.81$, $SD=4.17$), consistent with our hypothesis. The average self-esteem scores among identity moratorium and identity foreclosure were more similar to the average self-esteem scores among identity diffusion (See Table 3 for more detail).

Aim 4: To investigate survivors' self-perception and its relationship with identity

The self-perception profile for adolescents assesses how AYAs perceive themselves. The self-perception scale consists of an overall mean and six subscales which include: social acceptance, athletic competence, romantic appeal, close friendship, physical appearance and global self-worth. Means and standard deviations by subscale can be found in Table 3. There were no significances found with self-perception by participants' age at study participation, age at cancer diagnosis or gender. Descriptive statistics for each subscale by identity status are available in Table 3. We looked at the differences in self-perception by identity status. One way ANOVAs were significant indicating a main effect for identity status on self-perception, $F(1,153) = 4.33$, $p < .05$. Post hoc analyses using Tukey post hoc criterion for significance indicated that athletic competence differed between identity diffusion ($M=2.36$, $SD=0.87$) and identity moratorium ($M=2.84$, $SD=0.84$), as well as between identity diffusion ($M=2.36$, $SD=0.87$) and identity achievement ($M=3.01$, $SD=0.62$). There were also significant differences found on physical appearance between the identity diffusion ($M=2.8$, $SD=0.78$) and identity moratorium ($M=3.26$, $SD=0.6$), as well as between identity diffusion ($M=2.8$, $SD=0.78$) and identity achievement ($M=3.39$, $SD=0.47$). There were no significant differences on social acceptance, romantic appeal, close friendship, and global self-worth by identity status. See Table 3 for greater detail on these analyses.

Discussion

The goal of the current research was to explore the identity status in adolescent and young adult cancer survivors and to examine the relationship between identity status with body image, self-esteem, and self-perception. While research on adolescent and young adult cancer survivors is rich, there is extremely limited research on the identity development in AYA cancer survivors. This research question is especially important because how AYAs adjust to their cancer experiences has lifelong implications for their quality of survival, yet little is known (Husson & Zabrack, 2017). The only identified study that investigated identity development in AYA cancer survivors, by Madan-Swain and colleagues, suggested that AYA cancer survivors were more likely to be in identity foreclosure than any other identity status (Madan-Swain, et al., 2000). This study informed our study hypotheses. Individuals in identity foreclosure strongly adopt the beliefs and positions of their parents or guardians without any self-exploration of their own. One reason that survivors might have a greater percentage of individuals in foreclosure is because of their reliance on others throughout, and perhaps beyond, the cancer experience. AYA cancer survivors typically rely on their parents or guardians significantly more than their healthy peers due to the need to make serious medical decisions (Prasad, et al., 2015). They also spend less time in school engaging with peers because of illness and treatment. For these reasons, previous research suggests that AYA cancer survivors will be less likely to explore different beliefs and positions with their peers so they are less likely to have the opportunity to self-evaluate and will blindly adopt beliefs and positions of their families (Chou & Moskowitz, 2016).

Despite this literature, we did not find in our sample that a greater proportion of AYA survivors were in identity foreclosure. Additionally, our research found no relationship between

identity status and the age at time of participation, age at diagnosis, or gender. Despite the hypotheses that we would find significant relationships between identity status with body image, self-esteem and self-perception, we had inconsistent findings. We found no relationship between identity status and body image. However, we did find a significant relationship between identity status and self-esteem, showing that the greater the self-esteem, the more likely the individual will be in identity achievement and the lower the self-esteem, the more likely the individual will be in identity diffusion. We also found a significant relationship between identity status and certain aspects of self-perception, including athletic competence and physical appearance. AYAs that were in identity diffusion perceived their athletic competence and physical appearance significantly more negatively than AYAs that were in identity moratorium or identity achievement.

One possible reason our hypothesis about finding a greater proportion of individuals in identity foreclosure in our sample may not have been supported might be due to the relatively older age of our participants. Prior literature indicates that most healthy individuals start exploring their possible selves during early adolescence and the process continues into young adulthood (Becht, et al., 2016). Studies have shown that identity status changes over time, with younger individuals typically being in the less mature identity statuses of diffusion and foreclosure, and older individuals being in the more mature identity statuses of moratorium and achievement. (Mumru & Thompson, 2003). In this study sample, the mean age at time of study participation was 21.8 and the average age at cancer diagnosis was 16.8. Because most of these individuals were already into their young adult years at the time of study participation, it is possible and in fact, likely, that they had more time and opportunity to explore their possible selves and other identities before study participation. They may have also had more time to

explore possible selves and identities before their initial cancer diagnosis as well. It is also possible that AYAs might have begun the process of self-exploration before their cancer diagnoses, and therefore their identity status was less affected by their cancer experience as compared to individuals that might be in the very beginning stages of self-exploration. The age of participants in Madan-Swain's study, ranged from 12 to 23 (M=17) years old, and participants had completed treatment on an average of 5 years prior to the time of the study (Madan-Swain, et al., 2000). The average age of their participants, both at the time of their cancer diagnoses as well as their age at the time of participation was much younger than our sample in the current study. This suggests that perhaps current age, and perhaps even age at cancer diagnosis, have a more significant relationship with identity status than the cancer experience itself.

We also sought to examine the relationship between identity status with body image, self-esteem and self-perception. The literature indicates that concerns about body image increase drastically from childhood into adolescence and young adulthood (Helms, et al., 2017). In a typically healthy AYA, negative body image is associated with a multitude of dysfunctional outcomes such as anxiety, depression, social challenges, and a poorer health-related quality of life (Helms, et al., 2017). Previous research also suggests that many AYA cancer survivors have a greater risk for negative body image, self-esteem and self-perception than their healthy peers (Stern, Norman & Zevon, 1993). Our study found that individuals in our sample scored more negatively on self-esteem than healthy peers in prior literature, and had moderate self-perception and body image scores.

The current research did not support the hypothesis that individuals with lower body image would be more likely to be in identity foreclosure and individuals with higher body image would be more likely to be in identity achievement. The average scores on body image were all

relatively moderate when compared to their healthy peers in previous published literature, and were relatively similar across each identity status group, indicating that AYA cancer survivors do not have a more negative body image despite their identity status. The moderate mean scores on body image overall are not consistent with previous research in AYA cancer survivors, suggesting that survivors may not be more likely to have a negative body image.

The current research is consistent with previous research demonstrating lower overall self-esteem in AYA cancer survivors (Evan, et al., 2006). We found that individuals in identity achievement had significantly higher self-esteem scores than those in identity diffusion, which is consistent with our hypothesis. Individuals that had already completed the process of exploring their possible selves and had committed to specific beliefs and morals had greater self-esteem than individuals that lack any commitment to beliefs and morals and are not in the process of actively exploring possible selves. The research suggests that self-esteem is related to the commitment to a certain self, therefore individuals in identity achievement who had committed to a set of certain beliefs and had a sense of self identity also had greater self-esteem, versus individuals in identity diffusion that had not yet committed to a set of beliefs and determined their self-identity, and had lower self-esteem.

Adolescence is a particularly vulnerable time where the perception of physical appearance strongly influences the sense of self due to the extreme changes occurring in the body that they must make sense of (Markey, 2010). Because how an AYA perceives themselves is strongly related to their self-image, it was hypothesized that individuals that had a more positive self-perception would be more likely to be in identity achievement. Out of the six subscales used in the Self-Perception Profile for Adolescents (social acceptance, athletic competence, romantic appeal, close friendships, physical appearance, and global self-worth), our

research concluded that only AYAs perception of their physical appearance and athletic competence were significantly related to their identity status. AYAs that were in identity diffusion perceived their athletic competence and their physical appearance significantly more negatively than AYAs that were in identity moratorium and identity achievement. Because there is typically such a strong influence on the perception of self that is based on the physical appearances of oneself throughout adolescence, it makes sense that there would be greater significance of physical appearance and athletic competence on identity status than the other subscales that are not as strongly based in physicality (Markey, 2010).

Strengths and Limitations

Adolescent and young adult cancer survivors are an understudied population. The current research provides greater insight into adolescent and young adult cancer survivors and the possible psychosocial and developmental consequences of the cancer experience. To the best of our knowledge, there is no previous research focused on identity development examining how body image, self-esteem and self-perception all relate to the identity development in this population. The sample size is relatively large for a group that can be especially difficult to study due to lower rates of study participation, and difficulty with accessibility and obtaining study consent. One limitation of the current study is the homogeneity of study participants, specifically that a majority of participants were predominantly non-Hispanic Caucasian, so it may be difficult to generalize our results to individuals from other racial backgrounds. The cross-sectional data is another limitation of this study because we were unable to examine any causal relationships or investigate any changes over time.

Future Research

Future research should consider conducting a similar study over an extended period of time. A longitudinal study would make it possible to examine how age and maturity may interact with body image, self-esteem, self-perception and identity status. Examining the relationship that puberty has with these factors would also be useful. There are a multitude of physical and emotional changes that are occurring simultaneously during puberty that may have significant effects on an adolescent's self-image as a whole, and enduring a cancer diagnosis and cancer treatments during this time can increase their vulnerability. Future research should also consider focusing on including a more diverse sample. Culture, ethnicity and race may have a significant effect on how AYAs perceive themselves and how much they like or dislike themselves and their bodies. Socioeconomic status may also play an important role, especially with respect to how health insurance and financial stressors may impact medical and emotional status.

Additionally, a direct comparison between AYA cancer survivors and their same age healthy peers may provide greater insight into how the cancer experience influences typical trends seen in AYA including self-esteem, self-perception, body image and identity status. Future research is critical for determining the psychosocial impact the cancer experience has on the already vulnerable population of adolescent and young adult cancer survivors. Assessing the psychosocial impact of the cancer experience on AYAs can have clinical implications that would be extremely useful for medical and psychological treatments moving forward.

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Table 1. Participants' Sociodemographic and Medical Characteristics (n=153)

	N	%
Gender		
Male	89	58.2
Female	64	41.8
Age at Diagnosis (M ± SD)	16.84 (1.9)	
14	16	11.0
15	31	21.2
16	22	15.1
17	20	13.7
18	23	15.8
19	17	11.6
20	17	11.6
Age at Questionnaire (M ± SD)	21.8 (2.55)	
16-18	18	11.7
19-20	31	20.3
21-22	43	28.1
23-24	28	18.3
25-26	33	21.6
Race		
White	140	91.5
Black/African American	6	3.9
American Indian or Alaskan Native	2	1.3
Asian/Pacific Islander	2	1.3
Other	3	2
Cancer Diagnosis		
Thyroid	37	24.2
Germ cell Cancer	32	20.9
Hodgkin's Lymphoma	30	19.6
Non-Hodgkin Lymphoma	16	10.5
Leukemia	11	7.2
Sarcoma	8	5.2
Carcinoma	6	3.9
Lymphoma	6	3.9
Other	7	4.6

Table 2. Frequency of Participants in Each Identity Status Category

Identity Status	Frequency (N)	Percent (%)
Identity Diffusion	44	33.1
Identity Foreclosure	22	16.5
Identity Moratorium	51	38.3
Identity Achievement	16	12.0
Total	133	100

Figure 1. Identity Development in AYA Survivors

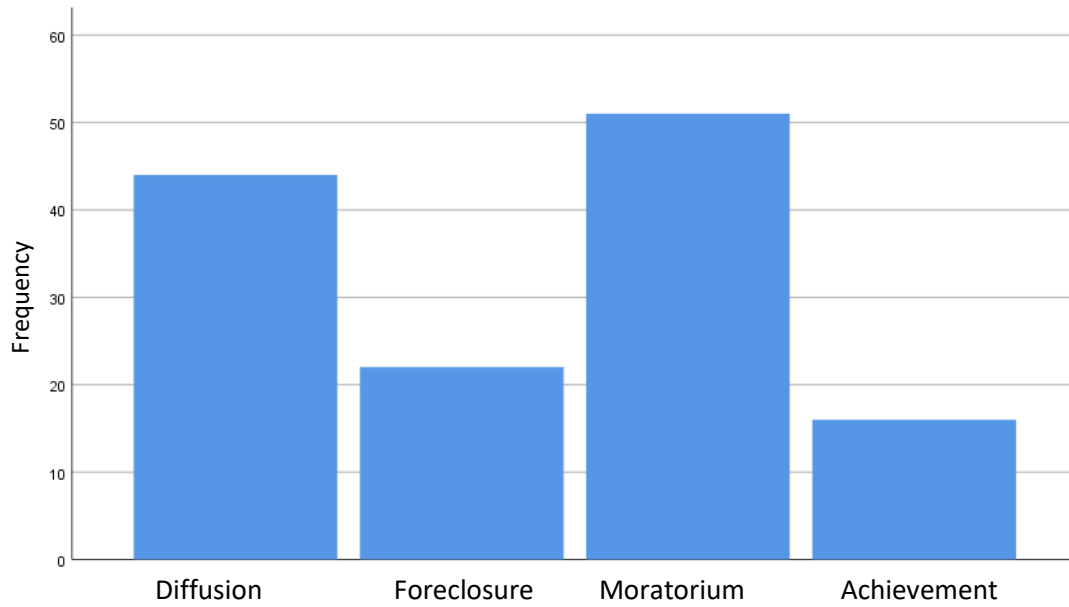


Table 3. Means and Standard Deviations for Body Image, Self-Esteem, and Self-Perception Subscales by Category of Identity Status

	Identity Status				p-values
	Identity Diffusion M (SD)	Identity Foreclosure M (SD)	Identity Moratorium M (SD)	Identity Achievement M (SD)	
Body Image					
Others' Reaction to Appearance	4.25 (0.54)	4.31 (0.8)	4.49 (0.5)	4.47 (0.55)	0.2
Body Competence	3.43 (0.79)	3.65 (0.79)	3.55 (0.66)	3.93 (0.72)	0.15
General Appearance	3.57 (0.66)	3.96 (0.66)	3.71 (0.6)	3.82 (0.56)	0.11
Value of Appearance	3.48 (0.5)	3.73 (0.61)	3.53 (0.42)	3.45 (0.42)	0.21
Body Parts	3.64 (0.59)	3.86 (0.71)	3.65 (0.87)	3.84 (0.78)	0.53
Self-Esteem					
Total Self Esteem	21.39 (5.39)	24.81 (4.62)	23.12 (5.27)	25.81 (4.17)	0.01*
Self-Perception					
Overall	2.83 (0.4)	3.01 (0.21)	3.08 (0.37)	3.05 (0.27)	<0.01*
Social Acceptance	3.05 (0.49)	3.17 (0.42)	3.15 (0.6)	3.08 (0.56)	0.74
Athletic Competence	2.36 (0.87)	2.54 (0.84)	2.84 (0.84)	3.06 (0.62)	0.01*
Romantic Appeal	2.81 (0.61)	3.00 (0.51)	3.00 (0.47)	2.78 (0.76)	0.26
Close Friendship	2.99 (0.4)	3.06 (0.35)	3.08 (0.49)	2.8 (0.52)	0.16
Physical Appearance	2.8 (0.78)	3.22 (0.59)	3.26 (0.6)	3.39 (0.47)	<0.01*
Global Self Worth	2.98 (0.51)	3.05 (0.19)	3.17 (0.44)	3.12 (0.2)	0.12

*p<0.05