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What Happens After Treatment: Improving Quality of Life in Adolescents and Young Adults

Nichole Smith 18
DePauw University

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Sponsor: Professor Ted Bitner

Committee: Professor Pascal Lafontant & Dr. Lamia Barakat

Abstract

More children and adolescents are surviving a cancer diagnosis now than ever before, but with these encouraging survival rates come the need for improved survivorship care. As a result of treatment, AYA are suffering from physical setbacks such as issues with weight management and fertility (Nightingale, 2011), and psychosocial setbacks such as PTSS, anxiety, and depression (Butler, Rizzi, Hardwerger, 1999). These factors may contributed to the fact that adolescents and young adults (AYA) often repot lower QOL than their healthy counterparts (Russell, Hudson, Long, Phipps, 2006), which highlights the need for interventions that address the unmet needs and QOL of AYA who have concluded cancer treatment. This study analyzes the PedsQL of AYA who have been diagnosed with cancer (n = 126) and healthy controls (n = 103) in order to determine if healthy controls report a higher PedsQL score than AYA. Additionally, I hypothesized that AYA on treatment will have a lower PedsQL than those off treatment, education would vary by diagnosis code, and diagnosis code would impact PedsQL total scores. Independent t-tests, Chi-Square tests, and Analysis of Variance (ANOVA) tests were conducted to test these hypotheses. These tests revealed that while healthy controls did have a higher total PedsQL score than AYA, AYA off treatment had significantly higher PedsQL total scores than those on treatment. However, the hypotheses that education level would vary by diagnosis code and that diagnosis code would affect PedsQL were not supported.

"That's why I came to Philadelphia, to take care of kids with cancer. Because at the time I came, there wasn't much else you could do, but care… I knew a lot of them were going to die; I could talk about dying. And I could talk to kids about dying." When asked to look back on the early days of her career Dr. Audrey Evans, gifted the moniker the 'Mother of Neuroblastoma,' honestly reflected back on her first days working as an oncologist at the Children's Hospital of Philadelphia (CHOP) (Modern Hero, 2017). She began working at CHOP in 1968, which was a time filled with high rates of mortality for pediatric oncology children and adolescents.

Before the 1950s, children with cancer were not offered clinical trials. Instead, the goal was to keep them comfortable, as it was considered unethical to put children through treatments with high toxicity when they would ultimately succumb to their illness (Jessop, 2015). However, in the 1950s, the Children's Oncology Group (COG) was created, and was ultimately devoted to researching childhood cancer. COG was responsible for creating clinical trials for treatments, which allowed for much needed new treatments to cure children of their cancers. Sidney Farber was one such individual who utilized the clinical trials that COG made possible. Dissatisfied with the current standard of care, Dr. Sidney Farber began to seek ways to treat, and hopefully cure, children with leukemia, which was one of the deadliest and most prominent forms of pediatric cancers of the time. Soon, Farber ensured chemotherapy became a common staple for treatment, and the mortality rates for pediatric leukemia children and adolescents began to decrease (Mukherjee, 2010). As a result of these promising results, oncologists began treating children with more intense chemotherapies during the 70s, resulting in increased survival

rates for osteosarcoma, Ewing sarcoma, and still increasing survival rates for children with leukemia (Jessop, 2015).

While this new drug was proving itself a promising alternative to the palliative care offered previously, Dr. Audrey Evans realized that children with neuroblastoma were still facing incredibly high mortality rates; therefore, she sought a way to mirror the survival rates she was seeing in other childhood cancers. In 1971, Evans developed the Evans Staging System, which successfully staged neuroblastoma before children began treatment. While this system was promising for children in the early stages of neuroblastoma as they were often treated with the chemotherapy that was saving other children, children with advanced stage Neuroblastoma were not treated to save them from undue suffering; Evans often encouraged these families to seek palliative care in an attempt to emphasize the quality of life for these children who would most likely not respond to the gruesome treatment (Modern Hero, 2017).

As the Evans Staging System assisted oncologists in determining the course of treatment for children with Neuroblastoma, the 1980s saw an era of both devastation and growth within the realm of pediatric oncology. While both bone marrow transplants and combined treatment of radiation therapy and chemotherapy were becoming common in treating children with leukemia, the children who had first been treated with chemotherapy in the 50s and 60s were starting to exhibit devastating late effects, which included deadly heart complications. Individuals began questioning the success of pediatric oncology research because very few new chemotherapy drugs were being developed, and

those that already existed seemed to have life-limiting late effects for their children and adolescents (Mukherjee, 2010).

Adults with cancer were already being treated with targeted therapies with lower toxicity, causing more alarm within the pediatric oncology community; therefore, research in the 1990s shifted from creating new drugs to understanding the biology of childhood cancers. Ultimately, researchers determined that the mutations within these cancers was vastly different than adult cancers; therefore, they were much more difficult to treat with the targeted therapies being developed in adult oncology (Jessop, 2015). These differences in mutations between adult and child cancers frustrated pediatric oncologists, but this research also allowed them to classify and stage these cancers at diagnosis in order to determine how intense the treatment needed to be; this meant that children with a lower stage cancer were not exposed to as much toxicity, which would hopefully decrease their late effects (Mukherjee, 2010).

As researchers began to shift their focus towards late effects and how they affected children and teens into survivorship, Dr. Anna Meadows emerged as an advocate for these children. She was one of the first doctors to discover that children who received radiation therapy to the head often suffered from cognitive deficits, and even secondary brain cancers. Meadows was familiar with new research findings that some cancers could be successfully treated with chemotherapy, instead of a combination of chemotherapy and radiation, and she began to advocate for these changes in cancers that had responded well to chemotherapy alone. She fought to modify treatments such that less drugs were

required to treat children, in hopes of lessening the late term effects. Her work earned her a position as the first director of the National Cancer Institute's Office of Cancer Survivorship, a role she fulfilled from 1996-1999 (New York-Presbyterian Cancer Care, 2017).

As individuals such as Dr. Meadows were working on improving the lives of children and adolescents into survivorship, researchers were also still focused on finding life saving cures for children with cancer. In the 2000s, researchers began to develop immunotherapies, which seemed to be the answer to the targeted therapies researchers had been looking for (Jessop, 2015). Yet, in this current stage of immunotherapies and often successful staging at diagnosis, pediatric oncology children and AYA are facing a mountain of complications. Many promising therapies are being developed; however, each of these therapies must be tested through clinical trials before they are available as a tried and true treatment. Just as the devastating late effects of chemotherapy did not appear for several years, these new drugs and immunotherapies may result in similar effects; however, most of these treatments, with the exception of FDA approved treatments for relapsed acute lymphoblastic leukemia, are not advanced enough to determine if this will be the case. For those individuals who either do not qualify for the clinical trials or decline to enroll on them, they are treated with chemotherapies that are known to cause these dangerous late effects. Additionally, within the realm of research, children have only recently begun to survive cancer; therefore, research about the needs that pediatric oncology children and adolescents face as they finish treatment is limited.

Much of the research focused on children and adolescents entering survivorship has addressed the late effects children are facing. Some of these effects are directly related to their treatment. For example, children who have undergone treatment for brain tumors often suffer from cognitive deficits and delays such as trouble focusing, or having the mindset of someone much younger than their actual age; these deficits can even result in emotional effects, such as having a limited social group (Barakat et al., 2015). As a result of treatment, some adolescents also struggle with maintaining their physical fitness due to fatigue, and others have felt rejected by potential partners because they are suffering from fertility problems as a subsequent result of treatment (Keegan, et al., 2012). Additionally, psychosocial late effects have become an issue during survivorship for children, adolescents, and even parents, as some suffer from post-traumatic stress disorder (PTSD) from treatment, and some may have increased anxiety and depression post treatment (Butler, Rizzi, Handwerger, 1996). These are just some of the cognitive, physical, and psychological negative late effects that have been examined in children and adolescents as they have entered survivorship, and each of these negative effects can lower the overall quality of life of these children. Therefore, research must also begin to shift towards determining how to maximize the quality of life of pediatric oncology children and adolescents after their treatment has concluded.

The Ethics of Pediatric Oncology Research

In order to ensure individuals receive fair medical treatment, health care ethics exist. These ethics deem that four criteria must exist for patients to receive fairness, entitlement, and equality: justice, beneficence, maleficence, and autonomy

(Feinsod, & Wagner, 2008). The ethics of pediatric cancer and it's research has proved most challenging for the AYA population in recent years, which may also be attributed to their poor life outcomes and the fact they are treated in both pediatric and adult settings. Children who are treated in pediatric settings are often treated at academic hospitals, whereas other children are treated through community-based practices; these differences in treatment are alarming because treatments are often not tailored to children or AYA, often excluding them from clinical trials even though their cancers are often resistant to tried and true treatments.

Justice

In regards to health care ethics, justice exists when a patient's treatment criteria is similar to those individuals in a similar situation, and consideration of their case is equal to all those involved in their community population (Feinsod, & Wagner, 2008). When considering whether AYA receive justice within oncology, we must compare their treatment to those who are both younger and older than them.

Adolescents who are between the ages of 15-39 years are part of the AYA population; therefore, their outcomes are often compared to those both younger than 15 and older than 40 (National Cancer Institute, 2006). When chemotherapy treatments were first being developed, AYA had higher survival rates than their younger counterparts; therefore, several of the pediatric trials only included patients younger than 18, so young adults were excluded from the trials even if they had pediatric cancers (Burke, Albritton, & Marina, 2007). In the early 2000s, though, researchers published the survival rates of child and AYA pediatric oncology adolescents. While there was about a 1.5% increase in survival rates per year for

children less than 15 years old, there was only a 0.5% increase in survival rate for adolescents between 15 and 24 year olds (Ferrari & Bleyer, 2006). AYA now have an incidence of cancer diagnosis eight times higher than children less than 15 years old; therefore, AYA are in need of the same improvement in treatment that researchers were seeking out for children in the 50s and 60s (Burke et al., 2007).

In order for AYA to receive adequate justice, they must be considered for the same treatments as their younger counterparts; however, this is often not the case. In fact, the Children's Oncology Group (COG) determines the eligibility criteria for clinical trials; enrollment availability on these clinical trials is essential for survival rates for AYA to increase. These clinical trials often have low age limits; there are only 30 COG trials with upper age limits that range from 25 to 30 years old (Burke et al., 2007). The fact that a portion of AYA are often ineligible for clinical trials may account for one of the reasons that only 10-15% of 15-29 year olds participated in clinical trials from 1997-2003; only two percent of 20-29 year olds were even enrolled in COG (Ferrari et al., 2006). This lack of enrollment in clinical trials may also explain why AYA have much lower survival rates 20 years post diagnosis than children who were diagnosed when they were younger than 15 years old (Bleyer, Viny, & Barr, 2006).

Ultimately, AYA's lack of involvement in clinical trials, and their exclusion from eligibility in criteria for some, indicates that AYA are not receiving the same justice as their younger and older counterparts. This lack of justice may be contributing to AYA's poorer life outcomes. If AYA struggle to obtain the same

justice as other cancer patients during treatment, then they likely face even bigger struggles as they enter the off-treatment phase of treatment.

Treatment in Pediatric and Adult Settings

One flaw within the treatment of AYA in the context of pediatric oncology is that there is not a set standard for where treatment should take place. A reason this may occur is because adolescents from age 15-39 are separated into two distinct categories; those in ages 15-19 are considered adolescent cancer patients, and individuals from ages 20-39 are considered young adults (Freyer, 2013). Hence, depending on if patients are either considered adolescents or young adults may determine whether they can even be seen in pediatric or adult treatment centers. This does also contribute to the lack of justice for AYA, as patients younger than 15 and older than 40 may be treated in a setting based on their age, when they should really be receiving treatment based on the type of cancer they have; therefore, this is another area where AYA are not even necessarily guaranteed equal consideration within their own population as they may receive treatment in vastly different settings.

The availability of clinical trials is also dependent on the setting a patient is receiving treatment in. For example, if an AYA is being treated in an adult setting, that hospital may not be apart of COG; therefore, he/she would not be eligible for a potentially life-saving treatment. In contrast, there are some adult clinical trials that pediatric settings are often not privy to; therefore, some of the older young adults may not have knowledge about these trials if they are being treated in a pediatric setting. Young adults may also be treated in community-based practices; the

infrastructure of these practices cannot even support trials, so young adults are certaintly missing out on valuable trials in this setting. This disparity could be mitigated if pediatric and adult oncologists communicated these trials to one another, and infrastructure improved in community-based centers; however, oncologists in these three different settings are often reluctant to work with one another (Ferrari & Bleyer, 2006).

In addition to treatment disparities, survivorship is often complicated by the lack of cohesion in treatment settings. AYA appear to have a strong sense of independence and invincibility; therefore, they often downplay their negative symptoms, if they disclose them to their doctors at all (Ferrari et al., 2006). Recognizing symptoms such as fatigue, physical exertion, trauma, and stress is essential for AYA during survivorship because it could be a sign of either treatment recurrence, or late effects. However, if AYA have transferred from their pediatric setting to an adult one as a result of their aging and entrance into survivorship, then their new doctors may not be familiar with the symptoms they should be monitoring for both recurrence and late effects (Ferrari et al., 2006). This lack proper monitoring because of a switch in treatment setting could be devastating, and even deadly, for AYA who had finished treatment.

Room for Improvement

The Pediatric Oncology Branch of the National Cancer Institute (NCI) has recognized these ethical issues within pediatric oncology, and the ways that it affects AYA specifically (National Cancer Institute, 2006). As a result, they provided recommendations to improve the care for AYA and their families.

One of the most prominent recommendations made by NCI was to improve education, training, communication, and the quality of care for AYA. In order to do this, medical professionals in both pediatric and adult settings must receive the same training, which could eradicate the apprehension the two groups have with each other. In addition, the improved education and communication between the two groups could help achieve another one of the NCI's recommendations, which was to ensure that AYA are receiving excellent care during their entire treatment continuum, which ranges from prevention, screening and diagnosis, and all the way to survivorship and end of life care (National Cancer Institute, 2006).

NCI realizes that there is both an inconsistency in treatment due to the differences in treatment settings, and the lack of AYA enrollment on clinical trials that is preventing proper screening, follow-up, and treatment (2006). Additionally, the development of tools to monitor psychosocial effects of treatment is essential to improving care, especially as negative psychosocial effects may not be apparent until AYA finish treatment. However, grant funding for oncology research has become scarce, and most of this funding is aimed at identifying curative treatments (Burke, Albritton, & Mariana, 2007). In order to improve survivorship care for AYA, a recommendation of NCI, we must understand the research that has been done to improve their care as AYA complete treatment.

Quality of Life for AYA as they Finish Treatment

Often, people believe that going through treatment is the biggest hurdle of cancer; however, many people overlook the biopsychosocical struggles that evolve as AYA end treatment and enter survivorship care (Cantrell, 2007). Researchers

have begun to put an increased emphasis on measuring the quality of life (QOL) of AYA survivors in order to determine how their needs can be best met; however, QOL can be a difficult concept to measure. Cantrell (2007) explained that there are six major categories that contribute to AYA's QOL, and there are subcategories that go into those six as well: physical, psychosocial, personality, environmental, social, and future orientation. Through studying QOL in AYA survivors, researchers have been able to determine both positive and negative predictors of QOL, how parents can better support AYA QOL, limitations such as a difficulty in measuring QOL, as well as developed ideas for future improvements to survivorship care.

In addition to Cantrell' work, Nightingale and colleagues (2011) focused on conducting a meta-analysis in order to identify the domains of HRQOL for young adult survivors. This meta-analysis was groundbreaking, as it determined whether there are QOL domains that are neglected in the classical City of Hope framework, which was previously utilized to determine the effect of cancer and it's treatment on physical, psychological, social, and spiritual realms of cancer survivors. Through Nightingale et al.'s (2011) meta-analysis, they discovered that AYA survivors do tend to report psychological, social, and spiritual issues related to cancer and the subsequent treatment; however, other unique domains were identified that had previously been neglected from much of the HRQOL literature for AYA survivors of cancer. The meta-analysis determined that while physical functioning did appear to contribute to HRQOL, it was not as significant of a burden as the other domains, or some of the new ones that were identified. For example, fertility issues and sexual functioning were a significant concern of both males and females, whereas males

felt like their masculinity had been compromised by their potential infertility, and females felt like infertility may deter a future mate. Also, AYA reported that a change in body appearance (i.e. hair loss, weight gain/loss, scarring) made them feel less normal, and contributed to the social isolation they felt. While these two domains were negative factors that should be examined in QOL, the resilience of AYA was also a significant contributed to their overall HRQOL, whereas many AYA felt they had a positive orientation towards the future, that cancer positively changed their lives and identity, and that many felt like survivors interested in a healthier lifestyle instead of victims.

Both the positive and negative contributions to HRQOL such as the physical, psychological, social, fears of the future and of fertility, and resilience will be examined further through this section, and I will provide research on the ways to unite both the risk and resilience factors.

Protective Factors

A cancer diagnosis is often followed by significant change such as hospital stays, chemotherapy and/or radiation treatments, stem cell or bone marrow transplants, and physical changes such as fatigue, weight change, and hair loss (Manne, et al., 2002 ;Nightingale et al., 2011). However, there are protective factors that can promote a higher QOL, despite AYA's challenging circumstances. In order to develop programs that adequately address the needs of AYA post-treatment and increase their QOL, researchers must understand those qualities that can lead to a higher QOL.

Family Relationships. At the time of diagnosis and during treatment, AYA may become very dependent on their families. While they may still maintain close friendships, their parents and siblings are more likely to accompany them and be active participants in their treatment; therefore, researchers have wondered if AYA's relationships with their family members hold any bearing on their QOL as they conclude treatment and enter survivorship.

Orbuch, Parry, Chesler, Fritz, and Repetto (2005) hypothesized that if AYA reported an open and supportive relationship with their parents, then they would also have higher levels of coping and recovery as they entered survivorship. Ultimately, AYA who reported strong relationships with their parents did have significantly higher levels of well-being; survivors often reported a closer relationship with their mother than father. This parent-child relationship was important to the AYA and was the most significant in predicting AYA's psychological domain, especially in regards to their medical fears and how they approach and deal with their medical issues.

Roddenberry and Renk (2008) examined the level of concordance, or agreement, between mothers, fathers, and children and adolescents when they rated their QOL. Ultimately, they discovered that mothers' and children's' QOL ratings were significantly correlated; therefore, if mother's had a higher QOL rating, then there children were also more likely to report a similarly high QOL rating. This indicates that within the familial relationship, the pediatric oncology patient's relationship with their mother is incredibly important to their QOL during their treatment continuum, which likely extends into survivorship.

Barakat and colleagues (2015) were also interested in the role of family relationships in the physical and psychosocial QOL, particularly with survivors of childhood brain tumors. In their study, the survivors (*n* = 126) completed self-reports of their physical and emotional HRQOL, whereas the mothers of the survivors (*n* = 186) provided a caregiver-proxy report of their child's physical and emotional HRQOL. Ultimately, the survivors rated themselves with higher physical but lower emotional HRQOL that is typically reported by pediatric oncology AYA diagnosed with cancer that does not affect the brain. However, the mothers reported an inverse effect, describing their children as having a higher emotional HRQOL, but a lower physical HRQOL. Interestingly, family functioning had a significant main effect on the caregiver-proxy report of physical and emotional HRQOL; this effect existed only for the mothers, and not for the survivors. Hence, if the family functioned better, then the mothers had had a proxy report more similar to their children's perception of their HRQOL; whereas, a family that functions less adequately may negatively effect the mother's perception of her child's HRQOL. Therefore, the role of the family affects more than just the child and mother's QOL, but it also plays a role in how mothers' view their child's QOL.

Ultimately, studies examining the role of a patient's family in regards to their quality of life have suggested that both the strength of the parent-child relationship, as well as their mother's QOL ratings, indicate that AYA's relationships with their parents may have a significant effect of their QOL. Past research also indicates that the role of the family, and its ability to function after a cancer diagnosis, may report a mother's perception of her child's HRQOL. Future research should examine the

ways in which this relationship can be strengthened as AYA enter survivorship, and if strengthening this relationship would increase AYA's QOL ratings.

Benefit-Finding

A cancer diagnosis can be understandingly devastating for an AYA's current thought process. However, as Ferrari and Bleyer (2006) identified, AYA also have a belief in their own invincibility that no other age group seems to possess; therefore, their mood can bounce back to a level of positivity that can effect their QOL as they finish treatment. This idea is referred to as PTG, or benefit finding, where children and AYA survivors of cancer exhibit resilience from their treatment.

While PTG is a positive outcome of a cancer diagnosis for AYA, some individuals believe that it would either contradict the idea that PTSD may occur after cancer treatment, or that AYA cannot experience both PTSD and PTG. Phipps and colleagues (2014) wanted to assess PTSD and PTSS in AYA cancer survivors (n = 255) compared to healthy controls (n = 101), and whether their were factors that might mitigate the effects that may contributed to PTSD/PTSS. During this study, AYA and healthy controls were asked to describe their most traumatic event and answer questions relating to that event in order to determine if they exhibited PTSS or PTSD associated with the event. Additionally, Phipps and colleagues (2014) assessed AYA and healthy controls perceptions of the benefits and burdens associated with the specified traumatic event. Overall, 52.6% of the AYA identified a cancer-related event as their most traumatic event, but this differed by the time post diagnosis; AYA less than five years post treatment identified cancer as the most traumatic event 50% of the time, while those more than five years post diagnosis

reported cancer as the most traumatic event only about 24% of the time. Additionally only seven of the 255 AYA met criteria for full PTSD; out of these seven, only two of the AYA reported events that were related to cancer treatment. Hence, the amount of AYA who endorse PTSD is very similar to the national norms for healthy controls. Even more importantly, AYA endorsed significant benefits and growth to the specific traumatic event as compared to healthy controls. Therefore, AYA do report cancer as a traumatic event frequently when they have recently completed treatment, but they often report growing and benefitting from this event, and they rarely meet PTSD criteria based on their perceptions of this event.

Barakat and colleagues (2005) also wanted to describe PTG following childhood cancer survival. In this study, they assessed adolescent cancer survivors (n = 150), and their mothers (n = 146) and fathers (n = 107) at least one year post treatment. The majority of survivors, 84.7%, reported at least one positive consequence of having cancer, whereas a third of survivors reported four or more positive consequences; these positive changes were items such as positive changes in self, strengthened relationships with others such as family members, and plans for the future. Ninety-percent of mothers also reported at least one positive outcome, while 86% reported that their child's diagnosis had a positive impact on how they thought about their life; fifty-eight percent felt that they treated others better as a result of their child's diagnosis. The fathers also reported a positive change post diagnosis (62%). While these positive changes indicate that many survivors experience PTG post diagnosis, there was a positive correlation between PTG and PTSS. However, this finding indicates that even those adolescents who

experience PTSS from their diagnosis and treatment can experience positive changes and growth post diagnosis, which could higher their overall QOL.

When attempting to explain QOL in childhood cancers, Cantrell (2007) explained that possessing positive attributes, like courage, resilience, and hopefulness, was a significant correlate in order for pediatric oncology survivors to possess long-term psychosocial well being. Eiser and Eiser (2007) found that positivity, specifically optimism, does play a key role in QOL. They asked mothers of children diagnosed with Acute Lymphoblastic Leukemia (ALL) to assess their children's quality of life at diagnosis, one year later, and once again two years post diagnosis. Most AYA's QOL was impaired at diagnosis; however, their QOL significantly improved at the year one measurement, and tended to remain high at the two-year assessment. Those mothers who reported high levels of optimism in their children at the time of diagnosis also reported significantly higher levels of QOL and child's current mood at two years post-diagnosis.

Patterson, Holm, and Gurney (2004) were interested in determining which factors parents perceive to be helpful when dealing with and managing the cancer diagnosis. One aspect of their study was to ask the parents about their children's experiences during their cancer treatment continuum, and how they believed their children coped with their cancer. Out of the 26 parents who were interviewed, 77.8% of them indicated that their children used positive coping behaviors including holding positive attitude about their diagnosis and using humor to cope; these parents believed that the positive coping behaviors their children exhibited played a role in their higher QOL. Similar to Patterson et al. (2004), Stam,

Grootenhuis, Caron, and Last (2006) also discovered that AYA survivors who were optimistic at diagnosis and during the course of their disease tended to have a better QOL compared to those who were not as optimistic.

When determining whether PTG and benefit-finding can improve QOL in AYA, research overwhelmingly supports the idea that many AYA have found positive consequences as a result of their diagnosis, and have grown significantly. Even several parents of AYA have endorsed that their children often cope positively with their diagnosis and subsequent treatment, as well as an improved positivity and QOL post treatment. While PTG is likely not mutually exclusive from PTSD, the resiliency and growth that results from AYA being diagnosed with cancer will likely be beneficial in improving the QOL of AYA as they conclude treatment and enter survivorship.

Risk Factors

While there are protective factors that may contribute to a higher QOL in AYA, there are understandably negative aspects to a cancer diagnosis that may correlate with AYA reporting a lower QOL. These aspects must also be given considerable research because programs aimed at increasing QOL for AYA after treatment must also be able to address any negative facets of the AYA experience.

Mother-Child Relationship. Research has addressed the positive role that family's play on AYA QOL; however, one must wonder if families can play a negative role as well. Additionally, mother's appeared to play a significant role in the QOL of their children; therefore, research has also examined whether lower psychosocial

functioning in mother's can effect the QOL of their children who have been diagnosed with cancer.

Roddenberry and Renk (2008) discovered negative characteristics, along with the aforementioned positive ones, that contributed to both the concordance between parent and children's QOL. They asked both mothers (n = 47), fathers (n = 16), and children (n = 19) ages eight to 19 years old to report on their psychological well-being, as well as the child's quality of life. They discovered that mothers who reported increased symptoms of depression, anxiety, and parental stress reported significantly lower QOL in their children; their children also had significantly lower QOL scores. These findings indicate that mothers with higher levels of psychological symptoms, such as depression and anxiety, may impact their child's QOL rating in a negative way.

Vance, Morse, Jenney, and Eiser (2001) were also interested in the role that parental health might play on pediatric oncology AYA's QOL. Similar to Roddenberry and Renk's (2008) findings, Vance and colleagues discovered that children (mean age = 8.92 years) who had a lower self-reported QOL had mothers who reported higher levels of depression. In both studies, however, the fathers' psychosocial symptoms held little to no bearing on their children's QOL; this could be attributed to the fact that there was a low-response rate from fathers, so these findings are not generalizable to all parent-father dyads.

Similar to the positive effects family's can play on a child's QOL, research suggests that families can have a negative effect on a child's QOL. Mother's seem to

have the most impact on their child, and mother's depression ratings seem to have a strong correlation with lower reported QOL in their children.

Socioeconomic Factors. Times of economic strain often contribute to a lowered QOL in all individuals. A cancer diagnosis, especially in the pediatric population, tends to be accompanied with significant economic strain; therefore, it is quite possible that a patient's socioeconomic status can negatively impact their QOL.

Kobayashi and colleagues (2008) examined the role that socioeconomic status plays on pediatric cancer AYA and their parents in Japan. They discovered that socioeconomic status was significantly correlated with QOL; therefore, a higher socioeconomic status was associated with higher QOL reports, and a lower socioeconomic status was associated with lower QOL reports. The loss of a mother or father's job had the biggest impact on QOL, meaning this factor contributed to the largest drop in QOL ratings. Unfortunately, a child's cancer diagnosis is often accompanied by one or both parent's losing their jobs, as the demanding treatment schedule often forces parents to miss work, which often results in parents being either fired or forced to resign. These findings indicate that AYA are not immune to the socioeconomic distress that their diagnosis places on their parents, and this distress can significantly impact their QOL.

Patterson, Holm, and Gurney (2004) also realized that 20% of the parents in their study discussed the financial strain their child's diagnosis placed on them. The parents often discussed the difficulty of either not being able to work, or only being able to work restricted hours in order to meet the demands of their child's

treatment. They also discussed the fact that their child's treatment was extremely expensive, and that expensive co-payment was often required.

Not only is cancer treatment incredibly expensive, but also different diagnoses' and treatment protocol can be more financially demanding on a family. If a child must undergo either a bone marrow transplant (BMT) or hematologic stem cell transplant (SCT), there can be additional financial strain on the family. Bona and colleagues (2015) aimed to explore the prevalence of poverty and financial strain associated with families of children who underwent BMT with their treatment. Eighty percent of families reported that at least one parent had disruptions with work, such as several missed workdays, due to the BMT. Even more drastic, 12% of families reported one parent quitting their job or being laid off as a result of the transplantation, and 20% of families reported losing more than 40% of their annual income; families who were low income before transplantation were more likely to be affected by decreased pay or loss of job than families who were at or above the nation's annual income. In order to cope with the financial loss resorting from BMT, families often sold person property (22%), took out a loan or mortgage to cover costs, or incurred credit card debt in order to pay for their child's treatment. While some families were able to find ways to compensate for their financial loss, 26% of families reported that they were unable to pay their bills because of the financial hit they took as a result of their child's BMT. Therefore, transplants can play a significant role in the financial strain placed on a family, which can ultimately affect the family and child's overall QOL.

Ultimately, a child's cancer diagnosis often contributes to significant financial strain, and in some cases can lower a family's socioeconomic status. While parents' may try to shield their children from this reality, children are often still affected by their family's socioeconomic status, and hence their QOL can be negatively affected.

Parental QOL

While there are clear positive and negative factors that contribute to patient QOL, programs intended to accommodate the needs of children as they finish treatment must also focus on improving the QOL of the children's parents. These parents may face a set of unique challenges, which may impact their QOL. For example, often parents who report a lower QOL also perceive their child to be more vulnerable, and they report more illness related stressors (Vance, Morse, Jenney, & Eiser, 2001); therefore, their experience, and the factors that affect their QOL must also be understood.

The familial relationships children and adolescents with cancer have is often seen as a protective factor. While this is often supported through research, there are some cases where treatment has negatively impacted families. For example, as aforementioned, Barakat and colleagues (2015) discovered that mothers of childhood survivors of brain tumors have a lower proxy report of their child's HRQOL when they report lower family functioning. Additionally, Roddenberry and Renk (2008) determined that mothers' and their children's QOL is significantly correlated; therefore, if the mother has a lower QOL rating, then this may negatively impact the child's QOL ratings. This research is further supported by Vance and colleagues' (2008) findings that children with lower-reported QOL had mothers

with higher reported levels of depression. Therefore, while the family can serve as a protective factor for children, past research often indicates that children's QOL is closely tied to the well-being and QOL of their parents, which can be detrimental if the parents report low QOL and HRQOL.

In Patterson, Holm, and Gurney's (2004) study, they examined both positive and negative aspects that can contribute to parents' perceptions of their child's cancer diagnosis, treatment, and recovery. Eighty-six percent of the parents discussed cancer related strains such as their child's sickness related to their treatment (loss of hair, fatigue, etc.), loss of their child's functional ability, and their child's lowered attention span. These strains are likely present in most, if not all, parents of children with a cancer diagnosis; therefore, coping behaviors for these strains should be provided. In addition, the parents in Patterson et al.'s (2004) study reported strains they felt their children were under such as fear about needing to receive more treatment, nightmares about past treatment, and fear about recurrence. Interestingly, parents felt that their children had more strains if they were older during treatment because they could comprehend what was happening to them; this indicates that AYA may suffer from a unique set of strains that their younger counterparts may be exempt from. Both the cancer-related and perceived children's strains negatively impacted the parents, and may contribute to a lower QOL.

Rini et al. (2004) was interested in the role that bone marrow transplant (BMT) specifically plays on mother's basic beliefs. They felt it was necessary to examine mother's basic beliefs at the time of transplant and one year post

transplant in order to determine if the BMT impacted mothers' beliefs and QOL. Most mothers tended to report lower basic beliefs such as negative self-worth at the time of BMT; however, many mothers had higher beliefs one-year post BMT. However, some mothers reported low basic beliefs at both BMT and one-year post BMT; these women also reported more lifetime traumas. When examining these traumas, Rini and colleagues discovered that most of the traumatic experiences occurred in the mother's childhood rather than adulthood. These findings suggest that a mother's childhood experiences may impact her more than adulthood, and if she holds poor basic beliefs like negative self worth, then it may be hard to overcome these ideals in a time of distress if she experienced trauma in her childhood. Therefore, programming and therapy should be aimed at assisting mothers' in delving into and overcoming past trauma in order to help them cope with the current distress of their children going through cancer treatment.

Manne and colleagues (2002) also investigated the role of BMT and SCT on mothers' cognitive and social processing. Ninety mothers of children undergoing BMT and SCT were assessed at the time of their children's BMT, three months post BMT, and then once more six months BMT. A majority of the mothers' endorsed symptoms such as difficulty concentrating and sleeping, feelings of detachment, and recurrent distressing recollections of their child's BMT experience. While these symptoms were often reported, only seven mothers were diagnosed with full PTSD six months post BMT, and six mothers were diagnosed with partial PTSD. However, there were predictors of increased post-traumatic stress symptoms (PTSS) at each time assessment. For example, at the time of BMT mothers' fear of the threat to her

child's life, distress, and feelings of not being supported by family and friends were predictive of PTSS severity at six months post BMT. However, when mothers were assessed three and six months post diagnosis, only their psychological distress were associated with their PTSS severity. While Manne and colleagues (2002) identified factors of increased symptom severity, they were not as successful in predicting factors that would lead to a formal diagnosis of PTSD; therefore, future research could be aimed at determining the factors that predict PTSD, and then developing interventions that mitigate the effects of those factors.

A child's cancer diagnosis is often accompanied with unimaginable stress, especially for the parents of the children and adolescents. The structure of familial support can be crucial to the parents' coping, and if this structure is lacking, their overall QOL can decrease. Additionally, the intensity of their child's treatment, which can include treatments such as BMT and SCT, can play a significant role on parent's QOL. Parental QOL can ultimately impact the QOL of the children and adolescents; therefore, research should also be aimed at improving the QOL of the parents of these children and adolescents.

Post-Traumatic Stress

A cancer diagnosis is often accompanied with prolonged hospital stays and procedures such as spinal aspirations, surgeries, and transplants (i.e. BMT, SCT) that are out of the ordinary and traumatic to children and adolescents. As such, some children and AYA may experience post-traumatic stress symptoms (PTSS), and even post-traumatic stress disorder (PTSD) as a result of their experiences with

treatment. PTSS and PTSD could impact the psychological well being of AYA, which could inherently affect their HRQOL.

Butler, Rizzi, and Handwerger (1996) documented the presence and frequency of PTSD in parents of both children on treatment (n = 30), and children off treatment (n = 42). Those parents of children on treatment were more likely to meet the criteria for PTSD than parents of children off treatment, and these PTSD positive ratings were highly correlated with family discord, and low social skills. Therefore, it appeared that parents of children who were off treatment were less likely to experience PTSD, or negative psychosocial consequences as parents of children on treatment.

Meeske, Ruccione, Globe, and Stuber (2001) were interested in the relationship between PTSD and the long-term outcomes of AYA who had been treated for cancer. Twenty-two percent of the AYA met the full criteria for PTSD. Of these twenty-two percent, most reported significantly lower annual incomes, and their medical late effects were more prevalent in this group. Additionally, PTSD positive AYA reported significantly lower annual incomes than PTSD negative individuals, as well as reporting lower QOL in all domains such as social functioning, emotional well being, and role limitations. Ultimately, meeting criteria for PTSD can inhibit the overall quality of life of AYA who have survived cancer; therefore, recognizing the signs and symptoms of PTSD is imperative to improving the long-term quality of life of these AYA.

Stuber et al. (1997) did examine the predictors of posttraumatic stress symptoms in the survivors of childhood cancers. Children and adolescents who had

a negative appraisal of life threat of cancer and had higher treatment intensity tended to be more anxious; higher anxiety scores had a significant correlation with PTSD symptoms. Therefore, individuals who were more anxious were more likely to exhibit these symptoms. Additionally, children who felt that they had poor family and social support tended to have a higher appraisal of life threat. In order to work on decreasing PTSS in the long-term, programs could be created to increase social support for children and AYA diagnosed with cancer, as well as to help with their anxiety during treatment.

Measurement

While there are validated and reliable measures for QOL such as the PedsQL, there are still flaws within measuring QOL (Varni, Seide, & Rode, 1999). One such flaw is that there is not a comprehensive way of studying QOL within the medical field. For example, some studies rely on parents' report of child's QOL in order to determine the patient's QOL, while others ask the children to report their QOL. Also, while measurements such as the PedsQL exist, there is not a comprehensive measurement in order to compare the norms for AYA cancer survivors compared to their healthy counterparts (Ewing, King, & Smith, 1999). In order to improve QOL in pediatric oncology children and young adults, it is important to effectively study QOL; therefore, considerable consideration should be given to the measurements that exist currently, and whether those measurements are sufficient.

Russell, Hudson, Long, and Phipps (2006) were interested in understanding the parent-child agreement in reports of QOL, and how QOL ratings in parents and children with cancer compared to healthy controls. As expected, healthy controls

reported the highest QOL ratings, followed by those individuals who had finished treatment who reported intermediate QOL ratings, and then those on treatment who had the lowest QOL ratings. In addition, parents of the healthy controls had the highest correlation of perceived child QOL to the child's QOL rating; there were only moderate correlations for individuals on and off treatment with their parents. This suggests that parents are better at predicting their children's QOL when they are healthy.

Also, Russel and colleagues (2006) identified areas of disagreement between the parent-child dyads within the pediatric oncology group. The parents often reported significantly different reports in regards to physical functioning, role limitations, body pain, general health perceptions, and self esteem. These findings mirror those of Vance et al. (2001), where parents perceived their children to be more vulnerable; the parents in Russel et al.'s (2006) study seemed to underestimate their children's ability, which may be due to the fact that they see their children as more vulnerable, where their children may perceive themselves to be more capable despite their diagnosis.

Matziou, Perdikaris, Feloni, Moshovi, Tsoumakas, and Merkouris (2008) also wanted to determine if there was a high level of agreement between reports of QOL between parents and children both on and off-treatment. The best agreement existed on the physical and school domains of the PedsQL (Matziou, et al., 2008), which is one of the measures utilized to measure QOL in pediatric oncology children; parents and children also had better agreement once the child was off-treatment than when they were on-treatment. The worst agreement existed on the

emotional and social domains, which is consistent with most behavioral checklists. There were also interesting correlations that existed with the parent-proxy reports. When children were on treatment, parents who only had received a high school education tended to have the lowest agreement with male children; mothers who had received higher education had the highest disagreement with female children. This suggests that socioeconomic status may also play a role in the parent-child dyads in perceived QOL.

At this point, several studies require proxy reports of QOL; therefore, parents are normally asked to report their child's QOL, and the children do not fill out these reports. Parent-proxy reports are especially relevant when children are on clinical trials and are too ill or too young to complete the relevant measures. This is why several current studies have examined whether there is high agreement between children and parents; while there is agreement in some areas, it is not uncommon for their to be areas of disagreement, which may be attributed to the fact that parents may see their children as more vulnerable than their children view themselves. While the parent-proxy report may be necessary for young adults who cannot read or fill out the QOL scales on their own; this problem can be easily solved within the AYA population. Many of these AYA are capable of filling out QOL scales independently of their parents; therefore, the proxy report is not necessary. However, parents reports of their own QOL may be necessary to meet the parents needs as their children conclude treatment; therefore, measuring QOL for both young adults and parents is necessary, but each sample should be given the option of filling out their own QOL scale.

Uniting the Risk and Resilience Factors

Ultimately, there are a vast range of protective factors and negative contributions that can contribute to the long-term QOL and HRQOL of AYA and their families. Researchers have aimed to create a theoretical framework that could unite these risk and resilience factors. Anne Kazak has been transformative in both examining past theoretical frameworks, proposing her own, and developing interventions utilizing her theoretical framework.

In order to propose a theoretical framework and subsequent intervention, we must first understand past models that have been used to address the needs of childhood chronic disease. One past theory was based on a family systems perspective, which focuses on the idea that systems are composed of interrelated parts such that a change in one part would be associated with a change in all parts; however, researchers have criticized this model because many believe this model often neglects individual's disposition, contributions, and experiences (Kazak, 1989). Therefore, a model that would integrate systems theory as well as the development of individuals (i.e. contributions and experiences) was needed. Kazak (1989) proposed a social-ecological perspective, which emphasizes the relationship between the developing individual, and the settings and contexts in which the person is actively involved. Within pediatric psychology, this model proposes that the child is in the center of a series of concentric circles, and these concentric circles represent settings that influence the child; those circles that are further away from the child represent their societal values and culture, and those closest to the child represent their family, and peers from their neighborhoods and schools. Social-

ecology provides the framework for both assessment and intervention of chronically ill children that includes the child, their parents, siblings, extended family, and social support network.

Kazak and colleagues (2016) have utilized this social-ecological perspective when assessing the families of chronically ill children. In one such study, they wanted to assess the role of family ritual meaning on the financial burden and psychological symptoms of mothers of children with cancer. Ultimately, financial burden was positively associated with mothers' anxiety and depression symptoms; therefore, higher levels of financial burden were associated with higher levels of depression and anxiety. However, this relationship only existed when mothers reported low levels of family ritual meeting. In contrast, if mothers' reported that events such as family dinners had special family meaning, then they did not endorse higher levels of depression and anxiety, even if they did report significant financial burden. Therefore, utilizing the social-ecology framework of these mothers' by assessing their inner (familial ritual) and outer (financial burden) circles, they could better assess the relationship between financial burden and psychological well being of these mothers.

In addition to proposing a theoretical framework and assessing this model, Kazak and colleagues (1999) also developed an intervention that used both cognitive behavioral and family approaches in order to target anxiety, improve beliefs about cancer and treatment, social support, and improve family communication. The first two sessions were cognitive-behaviorally focused and targeted distressing memories, intrusive thoughts, avoidance, and arousal related to

cancer treatment in both parents and their children who survived a cancer diagnosis (*n* = 19 families). The last two sessions were focused on improving familial communication about the experience the family went during and after treatment. Not only did the majority of parents and children positively endorse the program, but also the symptoms of PTSD and anxiety improved from the beginning to the end of the intervention. Families also reported increased cohesion, orderliness, and gains in direction of their lives.

While there are several protective and risk factors associated with a child's cancer diagnosis, there have been few proposals in order to unite these factors in improving the QOL of AYA and their families. Kazak, however, has been transformative in creating a social-ecological framework in which the child, their family, their peers, and values are all included in improving their QOL. While these findings are preliminary, they are a starting point in order to create interventions to improve the QOL of AYA and their families after a cancer diagnosis and into survivorship.

The Role of Cancer Type

The type of cancer AYA are diagnosed with can play a drastic role in their quality of life, and how they will transition off treatment; specifically, children and young adults recovering from a brain tumor may have a subset of complications such as brain tumors, reduced cognitive functioning, and reduced social functioning that AYA with liquid and solid tumors may not struggle with (Barakat, et al., 2015). Due to the potentially increased physical and mental needs of children diagnosed

with brain tumors, the demands of the caregivers may also increase; therefore, cancer type could play a role in the overall QOL of caregivers.

An, Joung, Sung, and Kim (2013) sought out to compare intelligence, parenting stress, satisfaction, child efficacy, and intelligence of children with brain tumors on and off treatment. They discovered that children both on and off treatment had significantly lower HRQOLs than healthy controls, which would be expected. However, there was not a significant difference in HRQOL between children on and off treatment. These findings indicate that children diagnosed with a brain tumor tend to have a lower HRQOL, and this HRQOL does not improve once treatment has concluded. While this study compared children with brain tumors to healthy controls, the fact that children had similar HRQOL ratings on and off treatment sets them apart from children with solid and liquid cancers; often, these children with solid and liquid will have improved HRQOL post treatment (Russell, Hudson, Long, & Phipps, 2006). Additionally, intelligence often decreases in children from the beginning of treatment to the off treatment phase.

Hutchinson, Willard, Hardy, and Bonner (2009) were also interested in the psychosocial adjustment of caregivers of children with brain tumors who were on and off treatment. Caregivers tended to report higher levels of depression and anxiety on treatment than off of treatment; however, there was an interaction between treatment stage and intensity of the treatment the children received. Ultimately, caregivers of children with a higher treatment regime, such as surgery along with chemotherapy and radiation, reported higher levels of distress once their child was off treatment than parents of children with a lower treatment regimen.

Hutchinson et al. (2009) felt that there study was limited, however, because many of the children had not began to develop late effects from treatment; therefore, they hypothesized that parents may start to report significantly elevated levels of depression and anxiety as their children were off treatment longer.

Another anomaly within pediatric oncology is children and adolescents with brain tumors who are surgery-only neuro-oncology patients, meaning that the only form of treatment these children receive is surgery to remove their tumor. Meyer and Kieran (2002) sought to assess the psychosocial adjustment and needs of surgery-only neuro-oncology patients because this population is largely neglected in psychosocial research. The researchers interviewed 34 patient-parent dyads, and 13 of these dyads had recently completed surgery, whereas 21 were examined after a significant amount of time had passed from their procedure. Both short and long-term children and adolescents experienced elevated psychosocial adjustment problems within the realms of depression, behavioral problems, and academic adjustment; anxiety-related disorders were the only domain in which the children and AYA did not exceed the national limits for their respective age groups. Therefore, even children who do not have high treatment intensity are experiencing significant psychosocial complications off treatment.

Whereas children without brain tumors may be able to achieve a high HRQOL or adjust back to their lives as they conclude treatment, children with brain tumors, as well as their caregivers, often experience elevated levels of distress and psychosocial issues post treatment (Hutchinson, et al., 2009). This is likely due to the damage that may be done to the brain by the tumor, surgery to remove the

tumor, and subsequent treatment. As such, the needs of AYA recovering from brain cancers are unique from those recovering from solid and liquid tumors, and improving their QOL post-treatment may be more tedious; therefore, efforts should be made to address the needs of AYA and their parents as they enter the off-treatment phase.

Unmet Needs

In order to improve the care of AYA as they conclude treatment and enter survivorship, it is necessary to understand the areas where AYA have reported their needs have not been met. If researchers are better informed about the areas AYA feel there should be improvement, then they can start to target their efforts in order to improve the quality of life of AYA.

The *AYA HOPE Study Collaborative* was the first population-based study in the US aimed at characterizing HRQOL in a large cohort (n = 484) of newly diagnosed AYA. In order to be in the study, participants had to be between the ages of 15 and 39 years old, and been diagnosed with cancer between July 1, 2007 and October 31, 2008 (Keegan, et al., 2012). The survey identified both unmet information needs and unmet service needs. In order to determine AYA's unmet information needs, AYA were asked if they felt that they needed more information about various factors: cancer recurrence, cancer treatment, financial support, having children, meeting other cancer survivors, and talking about their cancer experience. Additionally, AYA were then asked to indicate whether they had received services such as participation in a support group, visiting a pain management specialist, professional advice for managing health care, and seeing

mental health professionals to name a few. The data collected from this survey has been analyzed and utilized by various researchers since the finality of data collection.

Keegan and his colleagues (2012) were interested in both identifying the unmet information needs of AYA in the AYA Hope Collaborative, but also identifying the various socio-demographic and health-related factors that are associated with those unmet needs. They discovered that 50% of the AYA reported needs that were specific to cancer and recurrence such as developing another kind of cancer, possible long-term side effects of treatment, and alternatives to treatment. Fifty-percent of AYA also reported unmet needs about staying physical fit, meeting with other survivors, nutrition and diet, financial support, and fertility. Alarmingly, a third of the participants felt that they needed to see a mental health care provider, and more than half of this third felt that this need had never been met. In terms of demographics, Keegan et al. (2012) found that participants who were older, were of either African American or Hispanic race/ethnicity, men, patients reporting worse overall health, and less than good quality of care were more likely to report that they had unmet needs than their counterparts. Overall, there were vast gaps in information and service needs, and there did seem to be an association between demographics, general health, and quality of care that contributed to these needs.

DeRouen et al. (2015) also analyzed data from the *AYA HOPE Study Collaborative*; they were interested in whether cancer-related unmet needs (recurrence, treatment, long-term effects, etc.) and a negative impact on perceived control over life could have a negative correlation to HRQOL. In order to assess

control over life, the *AYA HOPE Study Collaborative* asked AYA to indicate the overall impact cancer had on their needs, and how much control cancer had on their life. The results indicated that if AYA reported a significant number of unmet cancer-related needs and a negative impact of cancer on control of their life, then they were more likely to report a lower HRQOL. Therefore, future research could be aimed at improving self-efficacy within AYA to improve their feelings toward impact of cancer on control of their life; if a self-efficacy intervention was paired with decreasing unmet needs, then HRQOL may improve in AYA.

The *AYA HOPE Study Collaborative* was transformative in collecting data from AYA about their unmet needs, but other researchers have also studied the impact of unmet needs on AYA. Duffey-Lind et al. (2006) wanted to identify the needs of AYA who had recently completed therapy, as well as their needs within the first few years off of treatment. Researchers held focus groups with both AYA and their parents, and themes quickly emerged. AYA felt conflicted about the amount of information they should be in charge of, and felt a lack of trust with their primary care physicians' knowledge. Many AYA also felt isolated as they transitioned off of treatment, and that they did not receive enough written information about the off-treatment phase. Parents also identified unmet needs mostly related to their concerns of recurrence and late effects in their children; however, they also doubted their child's primary care physician's ability to adequately treat their child. Ultimately, this study found that AYA and their parents have several cancer-related unmet information needs, as well as difficulty transitioning from oncological care to a primary care physician. One solution to this problem could be to better inform

oncologists, as well as primary care physicians, of the potential fears of their patients, and to make sure they provide information over cancer-related issues such as signs of recurrence or ways to handle late-effects.

In order to improve the QOL of AYA, it is imperative to understand the ways in which AYA feel their needs are not being met. While there are measures, such as the PedsQL, to assess the QOL of AYA, these measures may not completely encompass the needs that AYA feel are not being met. The aforementioned research is transformative in laying out the needs AYA feel are not being met, such as information on recurrence, needing to see a mental health care specialist, and a lack of social support from peers experiencing cancer as they are. Incorporating such factors in the survivorship stage of treatment could be necessary in order to improve the QOL of these AYA.

Current Study

Most of this research on the QOL of AYA who have been diagnosed with cancer suggests that there are factors such as cancer type, time off treatment, and perceived social support that may inhibit overall QOL. When measuring HRQOL in AYA, many researchers and physicians rely on The Pediatrics QOL (PedsQL) survey, which is one of the only current valid and reliable measures for the AYA age group (Varni, Seid, & Rode, 1999). However, this measure does not have goal discrepancy QOL measures for AYA, and the items do not necessarily differentiate AYA survivors from healthy controls (Ewing, King, & Smith, 2009). Therefore, current research at the Children's Hospital of Philadelphia (CHOP) has been aimed at developing a QOL measure that would have a clear discrepancy for the goals of AYA, as well as being

capable of understanding the QOL across disease trajectory. One of the goals of their project was to test a new QOL measures, the Measure of AYA Goal-Based QOL (MAYA-GQOL) that applies a goal discrepancy model, in which AYA are asked to give their perception of attaining goals such as graduating high school or college. Researchers at CHOP hope that MAYA-GQOL will provide knowledge about areas of resilience and targets of intervention in order to ultimately improve psychosocial care, which could greatly improve the quality of AYA who are completing treatment. Additionally, this study assessed reasons why AYA may or may not be enrolling on Phase III clinical trials using a measure created at CHOP called the Pediatric Research Participation Questionnaire (PRPQ).

For this current study, I will be utilizing measures taken from the study on MAYA-GQOL and PRPQ at CHOP. The goal of this project is to determine if there are factors that contribute to the QOL of AYA. I believe that overall health (cancer versus healthy controls), treatment stage (on and off treatment), education level, and diagnosis code will impact the QOL of the AYA in this study. In order to measure QOL, I will be analyzing the PedsQL, which was also gathered during data collection for MAYA-GQOL. There are drawbacks to PedsQL; however, it is a valid and reliable measurement, whereas MAYA-GQOL is currently in the process of been validated. Additionally, I will be analyzing demographic variables, whether patients are on or off treatment, and the diagnosis code (liquid, solid, or brain tumor). I hypothesize that AYA with cancer will have a lower PedsQL than healthy controls, and AYA who are on treatment will have a lower reported PedsQL than those AYA who are off treatment. In regards to the AYA who have been diagnosed with cancer, I

hypothesize that education will vary by diagnosis code, specifically those who have a brain cancer will have a lower education than those with liquid and solid tumors. Additionally, I hypothesize that diagnosis code will impact quality of life, such that those diagnosed with a brain tumor will have a lower total PedsQL than AYA diagnosed with either solid or liquid tumors.

Method

Participants

AYA who were diagnosed with cancer were recruited from CHOP and the Hospital of the University of Pennsylvania (n = 126). These AYA had to have been diagnosed with cancer at the age of 15 or later, and not be in palliative care or the terminal phase of their cancer. AYA were recruited either in person, or by telephone.

Healthy controls were also recruited (n = 103). The AYA controls had to be currently healthy, and have no history of cancer or a chronic health condition. AYA controls were peer recommended, and were contacted by phone.

Both the AYA and healthy controls were required to be between the ages of 15 and 29, and the average age of the participants was 22.66 years of age. Forty-eight percent of individuals were male, and 51% of participants were female; one individual reported a gender of 'other.' The individuals reported their races, which were white (78.2%), African American (10.5%), Asian (5.7%), and other or multiple races (5.2%). The participants' highest level of education that was completed, or the highest degree they received, was also collected; individuals' education ranged from grade school (1.3%), some high school (15.3%), completed high school or GED

(13.1%), some college, vocational or training school (18.8%), associate degree (3.5%), bachelors degree (37.1%), to post-graduate education (10.9%).

AYA completed additional demographic information to determine their diagnosis code and treatment status. Ninety-one AYA were off treatment, whereas 35 AYA were still on treatment. Also, AYA had been diagnosed with liquid (27.9%), solid (21.4%), and brain (5.7%) cancers.

Materials

Participants who chose to participate filled out an online assessment through the REDCap at the Children's Hospital of Philadelphia electronic data capture system. The following measures are those that I will be analyzing for the current study.

Demographics. Diagnosis code and treatment stage were collected through AYA medical record review, and these measures were then verified during the AYA's online assessment. Both AYA and AYA controls were asked to provide their gender, age at time of the survey, education level, and race on the online assessment.

Peds QL. The PedsQL is a reliable and valid measure of QOL for children who have been diagnosed with a disease such as cancer (Varni, Seid, & Rode, 1999). The PedsQL has various subscales used to compute the total score, which are the school, physical, psychosocial, emotional, and social subscales. There are several PedsQL measures in existence that are specific for the age of the child; there are also parent-proxy measures, so the parents can fill the PedsQL out for their child if the child is either too young, or cognitively unable to fill the measure

out themselves. The current study utilizes the PedsQL for Adolescents and Young Adults.

Results

Data Analysis

In order to test the hypothesis that healthy controls will have a higher PedsQL score than AYA, an independent samples *t*-test was run. This test was used because the independent variable, AYA participant type, is qualitative with only two categorical values (healthy control versus AYA with cancer), and the dependent variable is quantitative (PedsQL score). This test evaluated the PedsQL score means between the healthy controls and AYA in order determined if their scores differ significantly.

To test the hypothesis that AYA off treatment will have a higher PedsQL score than AYA on treatment, an independent samples *t*-test was run. This test was utilized because the independent variable, treatment status, was qualitative and only had two levels (on treatment versus off treatment), and the dependent variable was quantitative (PedsQL scores). This test evaluated the PedsQL score means between the AYA off and on treatment, and determined if the scores differed significantly.

To test the hypothesis that education varied by diagnosis code, healthy controls had to first be removed from the analysis. Next, a Chi-Square test of independence was run. This test was used because both variables are qualitative, and we want to know if education and diagnosis code are independent of one another.

In order to test the hypothesis that diagnosis code can contribute to a lower PedsQL score, specifically that those diagnosed a brain cancer will have a lower PedsQL score than those diagnosed with a solid or liquid cancer, an analysis of variance (ANOVA) was run. This test was run because the independent variable, diagnosis code, is qualitative, and has 3 levels (brain cancer, liquid cancer, and solid cancer), while the dependent variable is quantitative (PedsQL score). This test determined whether the mean PedsQL scores differed significantly between those who have been diagnosed with a brain cancer, from those who were diagnosed with liquid and solid cancers.

AYA Type and PedsQL

An independent samples *t*-test was conducted to test whether healthy controls had a higher total PedsQL score than AYA. The test revealed that, as hypothesized, the healthy controls (M = 81.80, SD = 9.60) had a higher total PedsQL score than the AYA (M = 70.89, SD = 16.01), t (-6.07), p <. 05. An independent samples *t*-test was performed in order to determine if the healthy controls had higher subscales of the PedsQL. The tests revealed that healthy controls had a higher reported PedsQL on all of the subscales except the emotional subscale score; healthy controls (M = 69.46, SD = 16.98) did not significantly differ than AYA t (M = 66.08, SD = 19.05) ,(-1.4), p = .162 (See Table 1).

Treatment Status and PedsQL

An independent samples *t*-test was conducted to test whether AYA on treatment would have lower reported PedsQL scores than AYA who were off treatment. The test did support the hypothesis that AYA on treatment would have a

lower total PedsQL score, as the AYA off treatment (M = 73.08, SD = 15.88) did differ significantly from the AYA on treatment (M = 64.86, SD = 15.06), t (2.58), $p < .05$. Additional independent sample t-tests were ran to determine if AYA on treatment would differ from AYA off treatment on the various subscales of the PedsQL; AYA on treatment (M = 55.51, SD = 21.82) had lower physical sub score than AYA off treatment (M = 73.28, SD = 22.24), t (.81), p <.05. Additionally, AYA on treatment (M = 60.91, SD = 20.67) had lower school subscales than AYA off treatment (M = 71.81, SD = 20.34), t (2.53), p <.05. The AYA on and off treatment did not significantly differ on the physical, psychosocial, emotional, or social subscales of the PedsQL (See Table 2).

Education Level and Diagnosis Code

A Chi-Square test was conducted to evaluate whether education level was impacted by diagnosis code. The two variables were education level (grade school, some high school, completed high school, some college, associates degree, bachelors degree, and post graduate degree) and diagnosis code (liquid cancer, solid cancer, and brain cancer). Education and diagnosis code were found to be related, Pearson's χ^2 (10, N = 126) = 21.94, $p < .05$). However, the hypothesis that those with a brain cancer would complete a lower education those with a liquid or solid tumor could not be supported, as AYA with a brain cancers only accounted for 10.30% of the percentage within education, whereas AYA with liquid cancers accounted for 50.8%, and those with solid cancers accounted for 38.9% (See Table 3,Table 4).

Due to the fact that 55.6% of the expected counts had values less than five in the Chi-Square analysis, the data was corrected in order to control for education and

diagnosis values that would be less than five. Once these cases had been selected, the Associate's Degree and Post Graduate Degree values within education level were removed. The two variables in the analysis were education (some high school, completed high school, some college, and associates degree) and diagnosis code (liquid, solid, brain). Education and diagnosis code were not found to be related, Pearson's χ^2 (6, N = 86) = 9.47, p = .15). Therefore, the hypothesis that education would vary by diagnosis code was not supported (See Table 5, Table 6).

Diagnosis Code and PedsQL

A univariate analysis of variance (ANOVA) was conducted to determine whether diagnosis code, specifically being diagnosed with a brain cancer, would result in a lower PedsQL score. The scores were analyzed using between-groups ANOVA with diagnosis code (liquid cancer, solid cancer, brain cancer) as the independent variable, and the PedsQL score as the dependent variable. The omnibus ANOVA test revealed that there was not a significant difference among the mean PedsQL score displayed by the sample, F(2, 123) = .89, p = .41, η^2 = .02 (Table 7).

Discussion

The hypothesis that AYA would have lower PedsQL scores than healthy controls was supported. These findings support past research that healthy controls often have a higher reported QOL than AYA who have been diagnosed with cancer (An, Joung, & Sim, 2013; Russell, Hudson, Long, & Phipps, 2006). One surprising finding, however, was that AYA did not differ significantly from healthy controls on the emotional subscale of the PedsQL. Past research has indicated that AYA may have PTG post treatment, which allows them to see positive consequences post

treatment, positive changes in themselves, and a resiliency that their healthy peers may not necessarily possess (Barakat et al., 2005; Nightingale, 2011; Phipps et al., 2014). As such, the AYA in the current study may also be benefitting from PTG, which could account for their higher emotional sub scores.

The hypothesis that AYA on treatment would have a lower PedsQL score than AYA off treatment was also supported. Past research has also found that AYA off treatment tend to have higher HRQOL than those on treatment (Butler, Rizzi, & Hardwerger, 1996; Russell, Hudson, Long, & Phipps, 2006). In terms of subscales, AYA on treatment reported a significantly lower physical subscale than those off treatment. This could be because AYA on treatment suffer from physical drawbacks such as hair loss, fatigue, and struggling with weight management as a result of their current treatment that AYA off treatment likely do not experience (Keegan et al., 2012).

The hypothesis that education level would vary by diagnosis code was not supported. This hypothesis was based on past research that individuals with brain tumors often have cognitive deficits (An, Joung, & Sim, 2013; Barakat et al., 2015); therefore, I believed that if these cognitive deficits existed in the AYA with brain cancers in this study, then their education level would also most likely be lower (i.e. some college or below) compared to AYA diagnosed with liquid and solid cancers. There are various explanations as to why this hypothesis may not have been supported. First, there was a very small sample of AYA with brain cancers; therefore, finding a significant level would be increasingly difficult. Additionally, one of the criteria for this study was that individuals needed to be able to complete the

survey on their own; therefore, the AYA with brain tumors in this study may have achieved a higher level of education than the AYA with brain tumors in past research.

The hypothesis that diagnosis code would impact quality of life was not supported. As aforementioned, this hypothesis was largely based on past research indicated that the overall QOL of AYA with brain tumors is typically low (An, Joung, & Sim, 2013;Hutchinson et al., 2009; Meyer & Kieran, 2002). The lack of significance in this study is likely due to the fact that there were only 13 AYA with brain tumors in the study making a significant finding difficult, as aforementioned.

Limitations. One major limitation of this study was the lack of a generalizable population to Indiana. Childhood cancers affect children and adolescents in Indiana; however, there is only one major children's hospital, which is located in Indianapolis. For this reason, several children are likely treated in adult settings, or in child settings that may not be specialized to their disease. Additionally, there is only one survivorship clinic in Indiana at Riley Children's Hospital; therefore, there may be several unmet needs for children, AYA, and their families as they conclude their cancer treatment. As such, I desired to address the needs of this population in Indiana because research on survivorship and post-treatment is limited in this region. While I had promising leads and communication with statistical specialists at Community North in Indiana who felt that either they had a young adult population, or that they could get us contact with Riley Children's, these efforts ultimately ended with a recommendation to reach out for a sample via

social media. Therefore, research is still limited in Indiana, which can partly be rectified by utilizing a dataset from Philadelphia.

While the dataset from CHOP rectified the lack of a population in Indiana, this dataset also has drawbacks. For example, the sample size of the on treatment sample (n = 35) was relatively small compared to the off treatment sample (n = 91). Additionally, several of the hypotheses were based on past literature highlighting the impact a brain cancer diagnosis can have on the QOL of AYA; however, there was a very small sample of AYA with a brain cancer (n = 13), compared to AYA with liquid and solid tumors (n = 113).

Future Research

One way to improve research in the future would be to increase the number of AYA with brain tumors that are recruited, and finish, a study on QOL. Increasing this sample could allow for significant findings based on diagnosis code and QOL, as well as determine areas that AYA with brain cancers may struggle that those with liquid and solid cancers do not.

Additionally, increasing the sample size for AYA on treatment would be ideal in order to assess further the differences between QOL of AYA on and off treatment. AYA on treatment could also report their PedsQL on treatment, and then be assessed one, three, and five years post treatment in order to determine if their QOL improves. If there are domains that do not improve over time, then interventions can be specifically aimed at improving these domains while AYA are on treatment, in hopes of improving their overall QOL post treatment.

The best way to incorporate these findings should be aimed at creating interventions to improve the QOL of AYA as they conclude treatment. While AYA are reporting higher QOL off-treatment than they are on-treatment, they are still reporting lower PedsQL scores than healthy controls. This indicates that there is room for QOL to significantly improve in AYA post treatment, so they can have a QOL more similar to their healthy counterparts. The fact that AYA are reporting similar emotional subscales to healthy controls is promising; however, interventions should be aimed at increasing the school, physical, social, and psychosocial subscales as well in order to improve the life outcomes for AYA who are concluding their treatment regime.

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Table 1

Independent Samples t-Test

		Levene's Test for Quality of Variances		*t*-Test for Equality of Means			95% Confidence Interval	
		F	Sig	*t*	df	Sig (2-tailed)	Lower	Upper
Peds_Total Score	Equal Variances Assumed	31.87	.00	-6.07	225	.00*	-14.45	-7.36
	Equal Variances Not Assumed			-6.34	205.98	.00	-14.3	-7.52
Peds_SchoolF Subscale	Equal Variances Assumed	26.89	.00	-1.2	225	.00*	-16.46	-7.27
	Equal Variances Not Assumed			-1.33	202.83	.00	-16.25	-7.48
Peds_PhysicalF Subscale	Equal Variances Assumed	37.05	.00	-7.5	226	.00*	-24.48	-14.3
	Equal Variances Not Assumed			-7.9	199.63	.00	-24.23	-14.55
Peds_PsychosocialF Subscale	Equal Variances Assumed	17.82	.00	-4.54	225	.00*	-11.7	-4.62
	Equal Variances NotAssumed			-4.7	215.98	.00	-11.58	-4.62
Peds_EmotionalF Subscale	Equal Variances Assumed	1.92	.17	-1.4	226	.16	-8.14	-1.37
	Equal Variances Not Assumed			-1.41	224.58	.16	-8.09	1.32
Peds_SocialF Subscale	Equal Variances Assumed	14.49	.00	-4.7	226	.00*	-12.99	-5.32
	Equal Variances Not Assumed			-4.87	219.58	.00	-12.86	-5.45

Note. *Values significant at the .01 level.

Table 2

Independent Samples t-Test

		Levene's Test for Quality of Variances		*t*-Test for Equality of Means			95% Confidence Interval	
		F	Sig	*t*	df	Sig (2-tailed)	Lower	Upper
Peds_Total Score	Equal Variances Assumed	.44	.51	2.58	122	.01*	1.92	14.51
	Equal Variances Not Assumed			2.65	59.47	.01	2	14.42
Peds_SchoolF Subscale	Equal Variances Assumed	.06	.81	2.63	122	.01*	2.69	19.12
	Equal Variances Not Assumed			2.61	55.96	.01	2.53	19.28
Peds_PhysicalF Subscale	Equal Variances Assumed	.06	.81	3.99	123	.00*	8.96	26.57
	Equal Variances Not Assumed			4.02	60.26	.00	8.94	26.58
Peds_PsychosocialF Subscale	Equal Variances Assumed	.19	.67	1.65	122	.1	-1.03	11.39
	Equal Variances NotAssumed			1.68	58.67	.1	-0.99	11.35
Peds_EmotionalF Subscale	Equal Variances Assumed	.42	.52	-.14	123	.89	-8.14	7.07
	Equal Variances Not Assumed			-.14	58.61	.89	-8.27	7.19
Peds_SocialF Subscale	Equal Variances Assumed	.76	.39	1.43	123	.15	-1.83	11.45
	Equal Variances Not Assumed			1.41	57.19	.16	-2.03	11.64

Note. *Values significant at the .01 level.

Table 3

*Education * Diagnosis Code Crosstabulation*

			Diagnosis Code			
			Liquid	Solid	Brain	Total
Education	Some HS	Count	11a	9a	2a	22
		Expected Count	11.2	8.6	2.3	22
		% within education	50%	40.9%	9.1%	100%
		% within dx	17.2%	18.4%	15.4%	17.5%
	Completed HS	Count	15a	3b	6a	24
		Expected Count	12.2	9.3	2.5	24
		% within education	62.5%	12.5%	25%	100%
		% within dx	23.4%	6.1%	46.2%	19%
	Some College	Count	21a	12a	2a	35
		Expected Count	17.8	13.6	3.6	35
		% within education	60%	34.3%	5.7%	100%
		% within dx	32.8%	24.5%	15.4%	27.8%
	Associates Degree	Count	3a	2a	0a	5
		Expected Count	2.5	1.9	.5	5
		% within education	60%	40%	0%	100%
		% within dx	32.8%	4.1%	0%	4%
	Bachelors Degree	Count	13a	17a	1a	31
		Expected Count	15.7	12.1	3.2	31
		% within education	41.9%	54.8%	3.2%	100%
		% within dx	20.3%	34.7%	7.7%	7.10%
	Post Graduate	Count	1a	6b	2b	9
		Expected Count	4.6	3.5	.9	9
		% within education	11.1%	66.7%	22.2%	100%
		% within dx	1.6%	12.2%	15.4%	7.1%
Total		Count	64	49	13	126
		Expected Count	64	49	13	126
		% within education	50.8%	38.9%	10.3%	100%
		% within dx	100%	100%	100%	100%

Note. Each subscript letter denotes a subset of diagnosis code categories whose column proportions do not differ significantly from each other at the .05 level.

Table 4

Chi-Square Test

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	21.94	10	.02*
Likelihood Ratio	23.69	10	.01
Linear-by-Linear Association	1.28	1	.26
N of Valid Cases	126		

Note. 10 cells (55.6%) have expected count less than 5. The minimum expected count is .52. *Values significant at the .05 level.

Table 5

*Education*Diagnosis Code Crosstabulation*

			Liquid	Solid	Brain	Total
Education	Some HS	Count	11	9	2	22
		Expected Count	12.8	6.7	2.6	22
		% within education	50%	40.9%	9.1%	100%
		% within dx	22%	34.6%	20%	25.6%
	Completed HS	Count	15	3	6	24
		Expected Count	14	7.3	2.8	24.0
		% within education	62.5	12.5%	25%	100%
		% within dx	30%	11.5%	60%	100%
	Some College	Count	21	12	2	35
		Expected Count	20.3	10.6	4.1	35.0
		% within education	60%	34.3%	5.7%	100%
		% within dx	42%	46.2%	20%	40.7%
	Associates Degree	Count	3	2	0	5
		Expected Count	2.9	1.5	.6	5
		% within education	60%	40%	0%	100%
		% within dx	6%	7.7%	0%	5.8%
Total		Count	50	26	10	86
		Expected Count	50	26	10	86
		% within education	58.1%	30.2%	11.6%	100%
		% within dx	100%	100%	100%	100%

Table 6

Chi-Square Test

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	9.47	6	.15
Likelihood Ratio	10.01	6	.12
Linear-by-Linear Association	.82	1	.37
N of Valid Cases	86		

Note. 10 cells (55.6%) have expected count less than 5. The minimum expected count is .52. *Values significant at the .05 level.

Table 7

ANOVA

Peds_Total Score

	Sum of Squares	df	Mean Square	F	Sig
Between Groups	459.24	2	229.62	.89	.41
Within Groups	31067.81	121	229.62		
Total	31527.05	123			

Post-Hoc Tests

					95% Confidence Interval	
(I) Cancer Group	(II) Cancer Group	Mean Difference	Std. Error	Sig.	Lower	Upper
Liquid	Solid	-2.99	3.08	.33	-9.09	3.09
	Brain	3.04	4.87	.53	-6.61	12.69
Solid	Solid	2.99	3.08	.33	-3.10	9.09
	Brain	6.04	5.02	.23	-3.91	15.98
Brain	Liquid	-3.04	4.87	.53	-12.69	6.61
	Solid	-6.03	5.02	.23	-15.98	3.90