

Disparities of Marginalized Pediatric and AYA Oncology Patients

by

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## **Abstract**

The purpose of this review is to highlight the healthcare inequities faced by pediatric and adolescent young adult (AYA) oncology patients; highlighting disparities in treatment faced by racial/ethnic minorities, individual identifying as part of the LGBT+ (Lesbian, Gay, Bisexual, Trans, Queer and other sexualities and/or identities) population and those with differing abilities. We review known barriers and disparities that exist for these select groups and provide an overview of potential evidence-based changes that could be implemented to address some of these inequities.

*Key words: pediatric oncology, healthcare disparities, marginalized groups*

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## List of Abbreviations

ADA	Americans with Disabilities Act of 1990
ALL	Acute Lymphocytic Leukemia
AML	Acute Myeloid Leukemia
AYA	Adolescents and Young Adults
CAR-T	A type of immunotherapy created with modified patient blood cells
CNS	Central Nervous System
COG	Children's Oncology Group
DAs	Differing Abilities
IOM	Institute of Medicine
LCCC	Lineberger Comprehensive Cancer Center
LGBTQ+	Lesbian, Gay, Bisexual, Trans, Queer and other sexualities and/or identities
Lly	Lymphoma
MIBG	Iodine 131 Meta-iodobenzylguanidine is a radiopharmaceutical used to treat pediatric neuroblastoma
NC	North Carolina
NCCH	NC Children's Hospital
NCCS	National Children's Cancer Society
NCI	National Cancer Institute
PHO	Pediatric Hematology & Oncology Division within the University of North Carolina School of Medicine
SOC	Standard of Care
UNC-H	Single entity of UNC HealthCare – including NC Children's Hospital & Lineberger Comprehensive Cancer Center
UNC-SOM	University of North Carolina School of Medicine
US	United States

## **PEDIATRIC AND AYA ONCOLOGY**

### Background

Pediatric oncology encompasses all solid and hematologic malignancies in patients between the ages of 0-21 (Cancer.gov, 2020). The two most common hematologic cancer diagnoses are leukemia (ALL) & lymphoma (Lly) while the most common solid cancer diagnoses are brain & central nervous system cancers (CNS). A new subspecialty that has emerged in the past ten years focuses on Adolescents and Young Adults (AYA) patients that have been diagnosed with any cancer between the ages of 13-39 (Lewis et al., 2014). Both pediatric and AYA oncology have unique trainings or fellowships that providers must complete; the care provided by both specialties cross over frequently and results in a collaborative relationship to ensure that any patient diagnosed between the ages of 0-39 have the best care and outcomes possible. Additionally, as pediatric oncology survival rates have continued to rise, patients live longer but now, must also deal with the long-term side effects of pediatric oncology therapy throughout their adulthood (O'Leary et al., 2008).

In the United States (US), there are greater than 10,000 new pediatric cancer diagnoses yearly; greater than 70,000 diagnoses for patients within the AYA range of 15-29 are diagnosed yearly (National Cancer Institute [NCI] Childhood Cancer, 2020; NCI AYA, 2020). Between 10-20% of these patients will die due to their malignancy - making cancer the leading cause of death for children and the fourth leading cause of death for AYA patients (NCI Childhood Cancer, 2020; NCI AYA, 2020).

### Long-term Effects of Pediatric or AYA Cancer Diagnosis

The implications of a pediatric or AYA cancer diagnosis exceeds just the physical effects that patients will experience during treatment; patients, caregivers and families can experience extensive financial, emotional, physical burdens (Dockerty et al., 2003; Vannatta & Gerhardt, 2003; Houtzager et al., 2001; Klassen et al., 2012; Rabineua et al., 2008).

As reported by Pelletier & Bona (2015), financial hardships affect a majority of the pediatric oncology population and affect families from all socio-economic groups (Pelletier & Bona, 2015). In fact, more than 1/3 of families will lose between 40-50% of their yearly income due to the cost associated with a family member's pediatric oncology diagnosis (Bona, 2014). While financial burdens may affect a majority of families, those in lower-income brackets are affected more significantly as the cost associated with treatment require a greater proportion of their income than their wealthier counterparts (Bona et al., 2014).

Understandably, caregivers suffer from emotional distress throughout patient treatment (Edmond et al, 2016). As many as 5-10% of caregivers and/or parents will develop posttraumatic stress disorder, while more than half will experience distress levels consistent with PTSD (National Children's Cancer Society [NCCS], 2018). Disparities in caregiver & patient distress have been reported, with racial & ethnic minorities and those with lower socioeconomic status reporting higher levels of distress (Nam et al, 2016)

Pediatric and AYA oncology patients can suffer from long-term side effects from treatment. These side effects can include physical side effects – such as reproductive or sexual dysfunction, cardia disease, neurocognitive deficits - as well as behavioral, psychosocial, financial, or other types of issues (Baker & Syrjala, 2018; Jacobs & Pucci, 2013)). More than 60% of pediatric and AYA patients will be diagnosed with a severe long-term side effect that will continue to place additional burdens of the patient (Kopp et al, 2012).

### Disparities & Barriers to Care

The disparities that exist among the quality, type and breadth of healthcare provided to patients – with or without a cancer diagnosis – have been studied over the past three decades. Certain marginalized groups have been found to receive poorer care as compared to their counterparts (Balsa et al., 2003; Penner et al, 2012).

Racial and ethnic minorities have been found to receive poorer care, have worse outcomes and have significantly more barriers to care than their Caucasian counterparts in the

US (Palanker, 2008 ). The Children's Oncology Group (COG) – the pediatric oncology cooperative group funded by the NCI to conduct pediatric and AYA oncology therapeutic and translational research studies – has reported similar trends among pediatric cancer patients, with racial and ethnic minorities experiencing worse outcomes and high rates of mortality. (Armenian et al, 2012; Morris et al, 2010).

Those from the LGBTQ+ population have also been found to have worse health outcomes than their hetero/cis-gender counterparts (Fredriksen-Goldsen et al., 2012). Research has also confirmed that those from the LGBTQ+ population that have a cancer diagnosis suffer worse outcomes and are not provided the same care offered to other patients (Fish et al., 2018).

Patients with DAs are those that have any restriction or diminishing ability to complete the tasks of everyday life like showering, eating or doing chores (NCI, 2020). Between 10-20% of the US population has DAs; the US has passed laws to address discrimination faced by those from the DAs (Shakespeare et al, 2009). This law outlines the protection in place for those with DAs as well as the federal guidelines for healthcare office space that can address the barriers that those with DAs typically face in the healthcare setting (ADA, 2009). Although this law was passed in 1991 and has been amended since there exist minimal changes in layouts of healthcare clinics and many of the barriers identified in 1991 still persist (Sherman & Sherman, 2011)

Pediatric and AYA cancers are considered rare – by NCI definition, rare cancers occur in less than 15/100,000 people per year (NCI, 2020). The limited number of patients has led to a lack of data about the general pediatric and AYA oncology population (Cahill & Makadon, 2013; Munoz-Blacno et al., 2017; Ortega et al, 2007; Clarke, 2019). It is fair to assume that if minimal data has been collected regarding pediatric and AYA oncology patients, there are even less data about those same patients that are parts of the group discussed above.



## Role of the UNC Healthcare System

The UNC Healthcare (UNC-H) system is a state-funded single entity that provides healthcare to the state of NC; the NC Children’s Hospital (NCCH) & Lineberger Comprehensive Cancer Center (LCCC) are both parts of the UNC-H system. NCCH is the only state-funded children’s hospital in NC and provides treatment to any patient, regardless of barriers that may affect a patient’s ability to receive care at other institutions (i.e. lack of insurance or ability to pay for service, immigration status, and lack of access to medical centers in rural areas). Per report (Gold, 2020), UNC treats pediatric and AYA patients that are from the marginalized groups mentioned previously – as well as patients that are undocumented, uninsured or any combination of the groups listed.

The UNC-H system is paid by and created to treat the citizens of NC; the UNC-H mission is, “to improve the health and wellbeing of North Carolinians and others whom [UNC-H] serve[s]” (UNC Health, 2020). To provide the people of NC with the best quality of care, it must a priority for UNC-H to address any disparities that exist. The author acknowledges that the changes that would be required to address every disparity that exists for any marginalized group would undoubtedly involve systematic changes that would take years – perhaps even decades – to implement. Nonetheless, there are ways that UNC could address some of these disparities to lessen the burden for the pediatric and AYA oncology populations treated at UNC.

As a first step, the author will provide a review of the disparities that impact the care provided to pediatric and AYA oncology patients from those groups identified previously - racial & ethnic minorities and those from the LGBTQ+ community. As patients with DAs face physical barriers, this population will also be included. For this review, our specific focus will be on the disparities in care for pediatric and AYA oncology patients.

## **DISPARITIES AMONG MARGINALIZED GROUPS**

### Disparities Encountered by Racial & Ethnic Minority Patients

Racial and ethnic minorities – including those that have immigrated to the US without proper documentation – face systemic barriers when seeking healthcare. As the population of the US continues to increase, the number of patients that will be affected by those disparities will also increase (US Census, 2020). There exist disparities in both the health of individuals and the healthcare access available to children from racial and ethnic minorities; these disparities are seen worldwide (Calza et al., 2016; Hacker et al., 2015; Goodburn, 2014; Flore, 2012; Gee & Ford, 2011; Chu et al., 2007)

In the US, pediatric patients from racial minorities are not provided the same information, do not receive the same quality of care and have worse outcomes than their Caucasian non-minority counterparts (Bhatia, 2011; Illowite et al., 2017). For caregivers from minority groups that speak non-English languages, language barriers harm the ability of caregivers to make an informed decision regarding treatment and correspondingly, those language barriers negatively impact the healthcare experience from the perspective of the caregiver (Zamaora et al., 2016).

Racial minorities are underrepresented in pediatric oncology research (Duma et al., 2017; Hamel et al., 2016); research shows that for these group many miscommunication issues exist before and during the informed consent process that may affect the willingness of patient participation in clinical trials (Simon & Kodish, 2005; Rick & Schabath, 2018). This is extremely problematic considering that within the pediatric oncology community, clinical trial enrollment is considered the standard of care (SOC) as treatment evolves quickly (Unguru, 2011). Within the US, Hispanic and African American patients do not participate in research as much as their non-minority counterparts that adds yet another barrier to quality healthcare on top of the other barriers these patient encounters (Aristizabal et al., 2015; Ford et al., 2007). Without the willingness of these patients to participate in research, the gap in quality of care continues to

widen and continues to hinder obtaining new information about those groups that could be used when attempting to address the disparities.

Undocumented patients face additional barriers to accessing quality healthcare, including fear of deportation, federal governmental action, or discrimination; lack of financial resources or stigma (Hacker et al, 2015). Undocumented patients both utilize healthcare services less than other groups and report worse experience in healthcare settings (Ortega et al, 2007). Providers for undocumented patients may also experience ethical dilemmas, which affects the type of care and treatment provided to those patients (Jepson et al., 2010). Providers may feel conflicted in wanting to provide oncology care for undocumented patients but there likely exist federal or state guidelines that may prohibit providing services to those without insurance or there may be a restriction (based on immigration status) for subsidized-care. Many healthcare organizations attempt to implement programs to address some of these disparities, but there are limited programs for undocumented patients and access to those programs is minimal (Nunnery et al., 2016).

#### Disparities Encountered by LGBTQ+ Patients

There also exist disparities in both the health, the healthcare provided to pediatric, and AYA patients that identify as part of the LGBTQ+ community (Institute of Medicine [IOM], 2011; Silberholz et al. 2017; Gibson et al., 2017. For instance, due to lack of disclosure of or LGBTQ+ status – from patient-to-provider or provider-to-patient -, patients that identify as LGBTQ+ are not provided adequate health information. Specifically, this population is often not provided information regarding risks that are known to increase for those that identify as LGBTQ+ (Quinn et al., 2014). Without the appropriate information, patients are not able to make educated decisions related to their healthcare – despite evidence that increased patient education improves outcomes (Boyle & Bubalo, 2007; Stromberb, 2005). When this population does receive care, it is often not an equivalent quality of care as provided to their non-LGBTQ+ counterparts (Kamen et al., 2015). As described by Eliason & Dibble (2015), healthcare

providers are rarely provided the training to fully understand the specific need of the LGBTQ+ population which unfortunately can result in disparities in care. Again, the lack of equal treatment for patients from this marginalized group will lead to worse outcomes and a greater burden for patients and caregivers.

#### Disparities Encountered by Patients with Differing Abilities (DAs)

Individuals with DAs have a similar incidence of a cancer diagnosis as those without DAs (Sullivan et al., 2004; Patja et al., 2001). There are subgroups of individuals with DAs, such as children diagnosed with Trisomy 21 (previously referred to as “Downs Syndrome”), who have a significantly higher chance of being diagnosed with acute lymphocytic leukemia (ALL) or acute myeloid leukemia (AML) than children without Trisomy 21– up to a 20-fold increased risk (Rabin & Whitlock, 2009; Hill et al., 2003)!

This population can encounter extensive barriers that are not as common with other marginalized groups – such as lack of disability awareness by providers, discontinuity of care or expectations of what is considered “normal” by healthcare providers (Acharya et al, 2017). Not only do these barriers affect the way these patients can navigate the healthcare system and receive appropriate treatment but they even affect the way these patients can physically navigate clinical spaces (Sakellarios et al, 2018). For instance, those in wheelchairs have been found to receive inconsistent physical evaluations and fewer screenings than their able-bodied counterparts; not surprisingly, these patients also **believe** they receive poorer care than other patients - which in fact appears to be true (Stillman et al., 2017). Again, the lack of equal treatment for patients from this marginalized group will lead to worse outcomes and a greater burden for patients and caregivers.

#### Implication of Disparities

Patients are multifaceted - and could be part of none, some, all or other marginalized groups than those described above. As mentioned, there is minimal research conducted on pediatric and AYA patients, and even less for those patients from marginalized groups - for

many patients, additional research is needed to be able to assess the niche barriers and disparities faced by those select patients (Magana et al., 2013). Many of the individuals in the groups listed above not only encounter the disparities listed but also face microaggressions (brief and commonplace daily verbal, behavioral or environmental indignities) - when interacting with providers and the healthcare system (Eliason & Dibble, 2015).

In the end – pediatric and AYA patients are not being provided the same care. Due to the disparities in care, there are specific groups that have worse outcomes, greater financial/social/emotional burden and are affected in a greater way than other patients. No pediatric or AYA patient could ever control or make any decision regarding their race, ethnicity, sexual orientation/identity or able-bodiedness – so why are those patients being provided worse care? These disparities can and must be addressed.

## **UNC PEDIATRIC & AYA POPULATION**

### UNC Demographics

Per a report from the PHO Division Chief (Gold, 2020), the PHO Oncology practice sees between 80-110 new pediatric & AYA cases per year; this number includes patients both newly diagnosed and those that have either relapsed or progressed. This number also includes those patients enrolled in clinical trials supported by PHO as many of the PHO research studies allow enrollment of patients greater than 18 years old – some studies even have no upper age limit and will allow enrollment of any pediatric, AYA or adult patients via a pediatric protocol.

Dr. Gold confirmed that between 30-50% of new patients each year self-report as minorities (African American, American Indian/Alaska Native, Asian or Pacific Islander); additionally, between 20-40% of new patients each year self-identify as Hispanic. Although no data has been collected in regards to the number of LGBTQ+ pediatric or AYA patients, it would be reasonable to assume there is at least one patient treated in the PHO practice per year that would fall in that group. Similarly, patients with DAs may have information about any DAs documented in their medical records, but the discrete number of patients with DAs that are treated by PHO is not documented. Again, it can be assumed that at least one patient treated in the PHO practice per year would fall into this group.

As the state-funded hospital created and maintained to provide the best care to all North Carolinians, UNC-H has a responsibility to address disparities for any pediatric or AYA patients discussed previously. Even if disparities only exist for a limited number of patients – even if only a single patient – those are still barriers that must be addressed for those patients to receive the best care possible.

### Changes in the UNC-H Pediatric and AYA Oncology Practices

Over the past 20 years, the PHO division has grown tremendously. Since 2000, both the number of providers treating patients and the clinical research staff have tripled. The number of clinical trials available for patient enrollment continues to increase with an average of 30-40

studies available for enrollment at a time. The type of treatment available and able to be delivered within UNC-H has also dramatically increased over the past 20 years. UNC-H can treat pediatric and AYA patients with many advanced therapeutic options that are not available at many other facilities such as MIBG treatment, CAR-T Cell Therapy, and stem cell transplant.

Another development in the care available to patients has been the creation of the AYA Program that provides care and support to patients treated at UNC-H between 13-39 years (LCCC, 2020). The creation of the program was funded by the Be Loud! Sophie Foundation (Be Loud!, 2019). The Be Loud! Sophie Foundation was created by the family of a former UNC-H AYA patient, Sophie, who wanted to find a way to address the specific needs of adolescents and young adults. With the creation of the AYA program, the PHO practice has been able to recruit providers that have completed both pediatric and AYA training in hopes to be able to address the specific needs of those patients and address any disparities that may exist.

## **MOVING FORWARD**

With such a large number of systemic sources of disparities and the ever-growing and changing population in the US, policy changes to either legislation or insurance will be necessary for many of these disparities to be addressed (Williams & Jackson, 2005; Hacker et al., 2015). US policy changes take decades – but in the meantime, organizations can begin to implement low-risk, high-reward interventions at the local level that can begin to affect the barriers for those marginalized groups (Krahn et al., 2006),

What is clear is that resources are needed in various modalities – from non-verbal communication (such as the use of sign-language or “charades”), interpreters, educational material for all involved with care, or trainings (Silberholz et al., 2017; Saeed, 2018; Pergert et al., 2008; Gibson, F, 2008). Training must be provided for all those associated with the treatment of patients – not just medical clinicians but all other types of providers that care for patients such as social worker, recreation life specialist, occupation/physical therapist, as well as clinic administrators (Davis, 2008 Glenn-Vega, 2002;). For many marginalized groups, clinical providers acknowledge their own lack of training and are eager to receive further education regarding these communities (Schabath et al., 2019, TJC, 2015; Griggs et al., 2017).

In the future, this review will be used as the foundation for a diversity and inclusion initiative that will begin the process to start addressing the disparities that are specific to patient seen within UNC-H. To be able to address the disparities encountered by patients specifically in the UNC-H system, data from those in the marginalized groups must be collected. Measures such as the Generic Short Patient Experiences Questionnaire could be used to collect information from these groups to assess how patients perceive their care and the disparities and/or barriers faced (Sjetne et al., 2011). This process could be completed during clinic visits in the inpatient or outpatient setting with collaboration from social workers or childlife specialist in the clinic that maintain a long-term relationship with families and patients throughout the entirety of treatment – which can last up to 4 years.



Once there is a greater understanding of the specific patient population of pediatric and AYA oncology patients at UNC-H, quality improvement initiatives could be created with the input from the various stakeholders involved. Using quality improvement guides such as those created by the Institute of Healthcare Improvement or Johns Hopkins to guide the quality improvement process would be a good use of resources already created (IHI, 2020; Johns Hopkins). A quality improvement plan would be created to provide guidance to UNC-H on how any evidence-based changes could be fully implemented to provide a more inclusive and equitable practice for all patients.

The most reasonable approach would be to start with low-cost, low-risk initiatives that can quickly affect patient care. For instance, clinical interpreters improve patient care and provide a way for clinicians and patients to ensure effective communication (Jugner et al., 2018); although there may be budgetary restrictions for hiring interpreters, there are many free software apps that can provide real-time translations and should be available for use with patients. Along with interpreters, clinic space should contain bilingual signage and translations of all patient-facing documents. Another low-cost, low-risk initiative would be to provide training to providers and clinical staff that address some of these disparities such as cultural competency training which is effective in improving the care provided to culturally diverse patient populations (Dabney et al., 2016). Utilizing the resources and tools of research that have been completed to address health care inequities and tailoring those resources and tools for the pediatric and AYA oncology population may a quick (and low-cost) way to address these disparities while further research is completed on the pediatric and AYA patient population.

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