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A Descriptive Study of Childhood Cancer Statistics: Montgomery County

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Jamie L. Hartig

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Abstract

Objective: This research describes childhood cancer and identifies variances in childhood cancer statistics in the United States, Ohio, and Montgomery County.

Methods: This is a descriptive analysis of childhood cancer statistics using the Ohio Cancer Incidence Surveillance System (OCISS) (Ohio Department of Health, 2010) and CDC Wonder database (United States Department of Health and Human Services [USDHHS], Centers for Disease Control and Prevention [CDC], & National Cancer Institute [NCI], 2008 & 2011.)

Cancer incidences between white children and black children were compared for the years 1999-2009. The OCISS database was also used to compare vital status by race, cancer stage and primary payer at diagnosis as factors related to childhood cancer in Montgomery County.

Results: Since the population in Montgomery County is 79% white and 20% black it seems like there is a higher incidence of black children with cancer, compared with the United States and Ohio; in actuality the incidence rates follow the population trend. Montgomery County had high incidences of late stage diagnoses compared to early stage diagnoses, and more than 50%, more black children were deceased compared to white proportions. There were two times more deceased cases with late stage diagnosis than with an early stage diagnosis. Medicaid as a primary payer was low and not an important predictor.

Conclusions: More research is required to elucidate the higher childhood cancer mortality rate for black children and the high number of late stage diagnoses. More parental education is needed on early childhood cancer warning signs to decrease late stage detections.

Keywords: childhood cancer, statistics, Montgomery County, Ohio

A Descriptive Study of Childhood Cancer Statistics: Montgomery County

There are many studies on childhood cancer, but there are not many that discuss prevention or risks closely associated with this disease. Childhood cancer is a sensitive subject since the population is considered vulnerable and because the disease is so rare among children under the age of 15. According to the National Cancer Institute (2008), only about one to two children per 10,000 will develop cancer each year, affecting about 10,400 children a year in the United States under 15 years of age. These low numbers make finding a cure, prevention, and associated risks hard for childhood cancer as opposed to other cancers that affect adults, such as breast cancer, with higher incidence rates that can be studied in larger quantities.

By studying the Ohio Cancer Incidence Surveillance System (OCISS) data (Ohio Department of Health, 2010), several advantages may present themselves. First, comparing statistics from Montgomery County to Ohio and the United States may identify trends that are prevalent in one area. Second, this data can be used to help allocate funding in an appropriate manner that could have the biggest impact. Finally, conducting a descriptive study of the cancer data in children may also encourage further studies to investigate why certain cancers are happening in a specific area. Overall, the purpose of this descriptive study is to identify differences in childhood cancer incidences and mortality rates in Montgomery County Ohio from, 1999-2009, compared to those in Ohio and the United States. Since prevention and risks are not widely known, it is important to know the cancers that are most prevalent in Montgomery in order to target interventions appropriately.

Statement of Purpose

The purpose of this descriptive study is to identify and describe cases of childhood cancer in Montgomery County, Ohio by using the Ohio Cancer Incidence Surveillance System (OCISS)

(Ohio Department of Health, 2010), 1996-2011. This dataset will allow an examination of trends in the area and comparisons will be made between Montgomery County, Ohio, and the United States using data that is publically available.

Review of Literature

Background

While childhood cancer incidence rates have increased over the past 40 years, from 11.5 per 100,000 in 1975 to 14.8 per 100,000 in 2004, mortality rates have significantly decreased (National Cancer Institute, 2008). The decline in mortality rate can be attributed to technological advancements in the medical community. Since the incidence rate of childhood cancer is still rising, more studies are being conducted to try to find causes of childhood cancer. This can be difficult though because the number of childhood cancer cases per year is low and is considered a rare disease. Current literature suggests that studies should be conducted focusing on the child's environment, genetic abnormalities, as well as maternal exposures. If more studies are conducted it may allow parents to have a better grasp on what is causing children to develop cancer and in return make more informed decisions on how to protect this vulnerable population.

Causes and preventive measures are not widely known for childhood cancer. This makes the disease harder to control because it is not apparent why children are being diagnosed with cancer. However, several studies are being conducted, according to the Children's Cancer Research Fund (2012a), to help establish some causes. These studies include exposure assessment in neonatal blood spots, drug therapies targeting cardiometabolic risk factors in severely obese children, and novel methods to characterize arterial health in children (Children's Cancer Research Fund, 2012a). These studies, once completed, will hopefully identify risk factors associated with childhood cancer and will make families more aware of how to keep their

children safe. Any type of childhood cancer research is important because the more knowledge gained the more protected children can become.

Types of Childhood Cancer

There are several different types of childhood cancer. Although the cancer develops the same as it does in adults (abnormal cells that grow uncontrollably), they are not treated in the same way as they are in adults. Each type of cancer is different in children and cannot be treated the same way every time (Children's Cancer Research Fund, 2012b). According to the National Cancer Institute (2008) there are 12 major types of childhood cancer. Children may develop a type of cancer that is more common in adults, but it is rare, and the types of cancer diagnosed in children are often different than the types of cancer we often hear about. The most common types of childhood cancer include leukemia, brain and other nervous system tumors, Neuroblastoma, Wilms tumor, lymphoma, Rhabdomyosarcoma, retinoblastoma, and bone cancer (American Cancer Society, 2012).

Leukemias are blood cell cancers and are the most common of the childhood cancers, they account for about 34% of all childhood cancer diagnosis (American Cancer Society, 2012). Although most are formed in the white blood cells it is not unheard of that the cancer forms in other blood cell types. This type of cancer is formed in the early stages of blood cell formation, which takes place in the bone marrow (American Cancer Society, 2012). Leukemias often overrun the blood fairly quickly and through the blood stream it can be carried into other parts of the body. Once the Leukemia is in the blood stream it can affect the lymph nodes, spleen, central nervous system, liver, as well as other organs (American Cancer Society, 2012). Diagnosis of Leukemia at an early stage is important to prevent further damage from the abnormal cells.

After symptoms of Leukemia are suspected there are several ways to diagnosis the child and determine which type of Leukemia is present in their body. Blood tests, lumbar puncture, bone marrow aspiration and biopsy, and lymph node biopsy are common tests used to determine if there are abnormal cells in the blood stream (American Cancer Society, 2012). To classify the type of Leukemia further there are more tests required which may include routine microscopic exams to look size, shape, and maturity of the blood cells, cytochemistry-which is a microscopic stain test to see if the cells react to the stains in a certain way, cytogenetics-which looks at the way the DNA is constructed, as well as many other tests that allow doctors to properly diagnose the type of Leukemia present (American Cancer Society, 2012).

Brain and other nervous system cancers are the second most common type of childhood cancer and make up 27% of all new cases (American Cancer Society, 2012). Brain and other central nervous system cancers are caused by an accumulation of abnormal cells in the brain or other parts of the nervous system. Although in other parts of the body the mass can be classified as benign or malignant and treated in different ways, even benign tumors on the brain and in the nervous system can cause serious harm to a child. A benign tumor elsewhere on the body will usually not invade any other parts of the surrounding area and is usually not seen as harmful. However, in the brain and other parts of the nervous system the tumor can begin to press on certain areas causing disability or even death. After a child has shown symptoms of a brain or nervous system tumor, diagnosis of cancer can be concluded through one of the following imaging tests- MRI, CT scan, PET scan, or through an angiogram (injects a dye into the blood vessels near the tumor and the image is looked at from an X-ray). After the diagnosis, a biopsy is conducted to see if cancer cells are present and to determine how much the tumor may have spread in the child. There are several ways to conduct the biopsy including a brain or spinal cord

biopsy, and a spinal tap. To check for the spread into other parts of the body, a bone marrow aspiration and biopsy may be conducted as well (American Cancer Society, 2012).

Neuroblastoma is a form of cancer that develops in the embryo or fetus and is rarely found in children older than 10. The cancer develops in certain types of nerve cells, in the sympathetic nervous system of the developing child, and is most often found in the abdomen (American Cancer Society, 2012). According to the American Cancer Society (2012), even though Neuroblastomas only account for 7% of the childhood cancer diagnosis, it is the most common cancer amongst infants. To diagnosis a child with Neuroblastoma there are several tests. A blood or urine catecholamine sample can be conducted, which measures the amount of catecholamine in the blood or urine, which is usually broken down and passed out on the urine. However, Neuroblastomas make enough catecholamine to be detected in the blood or urine sample taken (American Cancer Society, 2012). Imaging tests may also be conducted to determine if the disease has spread, if treatments are working, or to determine is a suspicious area may be cancerous. Finally biopsies are conducted because they are the only way to be certain that the diagnosis is correct (American Cancer Society, 2012).

Wilms tumor is a type of childhood cancer that develops in one kidney and on rare occasion both kidneys. It is most commonly found in children that are three years old and seldom found in children older than six years old. This type of cancer accounts for about 5% of all cancer diagnoses in children (American Cancer Society, 2012). A Wilms tumor diagnosis is usually brought around because of other symptoms a child is having. An early diagnosis is difficult because the tumor can grow rapidly without many other side effects to the child. If a kidney tumor is suspected, then the doctor would likely order imaging tests as the first tool in the diagnosis (American Cancer Society, 2012). Imaging tests such as an MRI, CT or CAT scan,

ultrasound, chest x-ray, or bone scans are used to determine if there is a tumor in the kidney, the likelihood that the tumor is a Wilms tumor, to see if the tumor has spread, and to determine if treatment or surgery has been successful. After the imaging tests have been completed, the doctor should have enough data to determine if the tumor is a Wilms tumor and then at that time surgery should be planned to have the tumor removed (American Cancer Society, 2012).

Lymphoma is a type of cancer that starts in the lymph nodes and may spread to other parts of the body. There are two major types of Lymphoma, Hodgkin lymphoma, also known as Hodgkin disease, and non-Hodgkin lymphoma. Both of these types of cancer can occur in adults and children. Hodgkin lymphoma is similar in adults and children and the types of treatments that are effective are similar as well. Children under five are rarely affected by Hodgkin lymphoma and account for 4% of the childhood cancer diagnosis while younger children are diagnosed with non-Hodgkin lymphoma, also accounting for 4% of all childhood cancer diagnosis; however children under three are still rarely affected (American Cancer Society, 2012). A biopsy is usually conducted to diagnosis Hodgkin lymphoma because enlarged lymph nodes are more often associated with infections than Hodgkin lymphoma. Like Hodgkin lymphoma, non-Hodgkin is usually diagnosed by biopsy. Staging and how much the disease has spread can also be determined by imaging tests (American Cancer Society, 2012).

Rhabdomyosarcoma (RMS) is a cancer that usually starts within cells that will eventually develop into skeletal muscles. It is most likely to occur in the head, abdomen, neck, pelvis, arms, or legs and accounts for about 3% of all childhood cancer diagnosis (American Cancer Society, 2012). Imaging tests will be conducted to help aid in diagnosis. They will determine if the area is cancerous, if treatment is effective, as well as how much the cancer has already spread. While the imaging will give strong evidence for Rhabdomyosarcoma a biopsy is the

only way to be certain. After the biopsy is conducted a lab test will be performed to determine if there are cancer cells in the sample and if there are if those cancer cells are RMS (American Cancer Society, 2012).

Retinoblastoma is a cancer that affects the eye. According to the American Cancer Society (2012), it also accounts for about 3% of all childhood cancer diagnosis. Children are most affected around the age of two and it is unusual for a child older than six to be diagnosed with Retinoblastoma. The diagnosis for Retinoblastoma is not usually achieved from a biopsy. In the case of this type of cancer, taking a biopsy could damage the child's eye and can usually be diagnosed with great accuracy by a doctor with experience with Retinoblastoma without the need for a biopsy (American Cancer Society, 2012). If a child is suspected to have Retinoblastoma the child will be referred to an ophthalmologist to take a closer look at the eye and to make the final diagnosis. When a child has Retinoblastoma it is not usually confused with other eye problems and it can sometimes be detected after a child has their picture taken. If a light is shined into an eye the pupil will look red because of the blood vessels behind it, but when Retinoblastoma is present the pupil will look white or pink (American Cancer Society, 2012).

Bone cancers usually affect older children and teens, but it is not uncommon for this cancer to develop at any age. There are two major types of bone cancer osteosarcoma which accounts for about 3% of all childhood cancer diagnosis, and Ewing sarcoma which accounts for only 1% of all childhood cancer diagnosis (American Cancer Society, 2012). Osteosarcoma is often found in fast growing bones, such as in the long bones of the legs and arms, while Ewing sarcoma is found in the bones of the pelvis, chest, or on the middle of the long leg bones. Both of these bones cancer can cause bone pain in the child. Just like most other cancers, if bone

cancer is suspected imaging tests, biopsies, and lab tests will be conducted to determine if it is cancer, how much it has spread, and if treatments are working (American Cancer Society, 2012).

Risks

Cancer remains one of the top causes of mortality in children. Even though the disease is rare, it is the number one cause of death by disease in children under the age of 14 (National Cancer Institute, 2008). Risk factors are important when dealing with a disease that is life threatening, though there are not many known risk factors for any of the childhood cancer types. Children are one of the most vulnerable populations and are dependent on their guardians and the knowledge of their physicians. While the studies of childhood cancer risks are limited, there are several that are able to link some behaviors and environmental factors to a higher possibility of developing childhood cancer. Flower and colleagues (2004) conducted a study on the risk of childhood cancer whose parents were exposed to agricultural pesticides use. The study showed that there was an increased risk of all cancer types overall, all lymphomas combined, and finally an increased risk of Hodgkin's Lymphoma. Also, the study concluded that there was an increased risk of cancer among children whose fathers did not wear protective gloves. This demonstrates the importance of safety gear when dealing with pesticides; not only for the parent, but also because of the increased risk on their child. The study also showed that for lymphomas, the difference between children whose parents had exposure to pesticides was almost two times higher than those parents that were not exposed. Zahm and Ward (1998) also looked at several studies linking pesticides use to childhood cancer and found similar results that showed several different types of cancer (leukemia, Neuroblastoma, Wilms' tumor, non-Hodgkin's lymphoma, as well as others) were linked to pesticides in several case-control studies as well as case reports. Agricultural over spray and drift are not the only pesticide use that parents should be aware of.

There are many different environments that can expose children to pesticides including homes, public buildings, schools, and even food or water contamination. This review by Zahm and Ward (1998) stated that a “survey conducted by the U.S. EPA found that 82% of U.S. households used pesticides with an average of three to four different pesticide products per home” (p. 894). These reports and studies show that there is sufficient data to suggest the link between pesticide use and childhood cancer, and that further testing on this matter should be conducted. When possible a parent should take into consideration their environmental surroundings and when possible limit a child’s exposure to pesticides due to increased vulnerability and susceptibility among children (Zahm & Ward, 1998).

Another risk closely associated with childhood cancer is road traffic. It is a known fact that occupational exposure to high levels of exhaust (which contain benzene) is a cause of acute leukemia in adults; however, the etiology of childhood leukemia is less studied. Amigou and colleagues (2011) studied the exposure of road traffic, and high levels of benzene, on children and the development of leukemia. This case-control study was conducted in France from 2003-2004, using 763 cases and 1,681 controls, all children under the age of 15. Several different variables were originated (proximity to road, flow of traffic, and NO₂ concentration) and Amigou and colleagues (2011) found that road traffic is related to the development of acute leukemia, specifically Acute Lymphoblastic Leukemia and Acute Non-Lymphoblastic Leukemia in children. This is a noteworthy find considering the risks of many types of childhood cancer are unknown. This will allow for further studies and more protection for children living in high traffic areas.

Although these are just a few risks associated with childhood cancer, there is research being completed to find out more risk factors to protect children from any type of childhood

cancer. Along with pesticide and traffic exposure, some cases of childhood cancer can be explained by several different conditions, such as Down syndrome, other specific chromosomal and genetic abnormalities, and ionizing radiation exposures (National Cancer Institute, 2008). The National Cancer Institute (2008) also points out that childhood cancer risks are unknown, but offers some insight into what studies are currently being conducted to find increased knowledge of associated risks. Studies on childhood cancer currently under investigation include medical conditions that were present during pregnancy or even before conception of the child with cancer, diet that the mother followed during pregnancy, and reproductive history of the mother. In addition to these studies, researchers are looking at the risks that may be associated with oral contraception exposure, fertility drugs, as well as other medications, family and genetic vulnerability as well as exposure to the human immunodeficiency virus (HIV) and associated risks (National Cancer Institute, 2008).

Symptoms, Treatments, and Therapies

Since injuries and infections in children are not uncommon some symptoms of childhood cancer, such as bruises or fevers, may be mistaken for an injury or illness. Parents should be aware of signs and symptoms as well have regularly scheduled checkups for their child. Some symptoms to be aware of include unusual swellings or lumps, energy loss, paleness, bruises easily, pain in one area of the body for a prolonged period of time, fever that is unexplained and does not go away, headaches or vomiting, sudden vision changes, or unexplained loss in weight (American Cancer Society, 2012).

The cancer treatment team is made up of doctors and nurses that are specialized in pediatrics and childhood cancer. The team consists of pediatric oncologists, which are specialists that use medicines to treat children with cancer, pediatric surgeons, radiation

oncologists, pediatric oncology nurses, which are nurses with a specialty in caring for childhood cancer patients, as well as nurse practitioners (American Cancer Society, 2012). It is important to have specialists of childhood cancer because the treatments and surgeries are different on a child than they would be on an adult.

After a team is formed, each child is treated differently depending on the stage and diagnosis of cancer. There are several treatments and therapies currently available to children with childhood cancer. Usually, the most effective treatment for childhood cancer is chemotherapy because this treatment is best for fast growing cancers. Chemotherapy is given in cycles because the medications not only affect the fast growing cancer cells, but any other type of fast growing cells as well. Once a cycle is over it gives the patient some time to recuperate and the healthy cells have a chance to recover (Children's Cancer Research Fund, 2012c). Chemotherapy can be given in several different ways, intravenous line, pill or liquid, injection, or intrathecal which means an injection into the lower part of the spine (spinal tap). Some of the side effects known are hair loss, anemia, trouble concentrating, fatigue, nausea and vomiting, as well as many others. Children's bodies are able to take and recover from higher doses than adults, so this gives the doctor a more effective way to treat childhood cancer if they can give the child a more rigorous treatment schedule (American Cancer Society, 2012).

Another treatment type is radiation. This type of treatment uses high-energy x-rays to target and destroy cancer cells. However, these rays can also kill or damage surrounding healthy cells, which can usually recover within a week (Children's Cancer Research Fund, 2012c). There are two types of radiation therapy, external radiation which sends the rays from the outside of the body to the location of the tumor and the less common radiation intraoperative radiation therapy which takes place during surgery. The side effects of radiation include, but are not

limited to, fever, fatigue, pain that does not go away, and skin breakdown or severe pain due to skin irritation (Children's Cancer Research Fund, 2012c).

Surgery is another alternative, although even after or during surgery, to get the best results radiation or chemotherapy drugs are often given (KidsHealth from Nemours, 2010). Bone Marrow Transplants (BMT) are another type of treatment used in childhood cancer. This treatment consists of intravenously injecting blood or marrow into the blood stream so that the blood-forming stem cells can help a patient recover those that were lost during treatment. There are three types of blood or marrow transplants. They include allogeneic which injects stem cells from someone other than the patient, autologous is when the patient receives their own stem cells, and syngeneic in which cells come from an identical twin. Although the autologous boasts some advantages, i.e. decreased life-threatening effects from the transplant and no risk of graft-versus-host disease the major drawback would be the risk of relapse (Children's Cancer Research Fund, 2012c).

Immune-based therapies (IBTs) are a rather new option for treating childhood cancer. When a cancer is resistant to other types of treatment, IBTs use the patient's own immune system to fight off the cancer and/or help reduce the side effects from the other treatment types. This is an ongoing development and researchers are working hard to come up with new IBTs that will be effective in treating childhood cancer (Children's Cancer Research Fund, 2012c).

Clinical trials are another way to get new treatments for a child with cancer. These clinical trials are developing and assessing new products, drugs, and therapies that may be more effective in treating childhood cancer (American Cancer Society, 2012).

Childhood Cancer Survival Rates

New medical technology and advancements in treatments have lowered the mortality rate in children with cancer over the past decade (National Cancer Institute, 2008). The five-year survival rate for the most common types of childhood cancer are all 66% or higher. Five-year survival rate means that the child with cancer has been treated and has survived at least five years, while many survived much longer than five years or were cured (American Cancer Society, 2012). The five-year survival rate for Leukemias are 82%, brain and other nervous system tumors are 71%, Wilms tumors (kidney cancers) are 89%, Hodgkin lymphomas are 95%, non-Hodgkin lymphomas are 85%, Rhabdomyosarcoma are 66%, Neuroblastoma are 73%, and Osteosarcomas (bone cancers) are 70% (American Cancer Society, 2012). The National Cancer Institute (2008) shows that the five-year survival rate has increased from 58.1% in 1975-1977 to 79.6% in 1996-2003.

Adult Survivor Obstacles

Finding risk factors is important because even after children beat the disease, their battle is not over. In the past, the chances of a child surviving cancer were slim, but now with medical advancements children are surviving cancer more often. However, the known effects of the children as they become adults were unknown until recently as more research is being conducted. Zebrack and Chesler (2001) look at the importance of providing childhood cancer survivors with the appropriate medical care, such as therapy, even after they beat the disease. They found that about 75% of children that are diagnosed with cancer will now beat the disease. The effect on their life in the future though has not warranted much research and in turn psychosocial support is lacking for these adults. It is not shocking that many survivors report having health-related worries even after many years of successful treatment and being cancer-

free (Zebrack & Chesler, 2001). The age at which a child was first diagnosed has a profound impact on the future outlook on life and their own self-image. If a child is diagnosed at a crucial developmental stage they may react to the future in a different manner than someone that is diagnosed at a younger age (Zebrack & Chesler, 2001). Some survivors have a positive outlook on life, they are happy for their survival, may become more mature, or have great clarity about life. One example that indicates the significance of age of the child at diagnosis includes the difference between a child diagnosed with leukemia and a child diagnosed with Hodgkin disease. Children diagnosed with Leukemia, which is diagnosed at an earlier age, are not as likely to report worries about body issues as those diagnosed with Hodgkin's disease, which is usually diagnosed later in the teen years. Those that are diagnosed with Hodgkin's disease may feel a greater impact because the disease has disrupted their teen years, and are more likely to report less confidence in their self-image. If many of these issues are not re-framed or diverted into something more positive, then these survivors will have a high level of psychosocial distress, more likely to engage in risky behavior, and overall a lower quality of life. These survivors as adults need more treatment in the psychosocial aspect of their lives to help balance out their issues and try to redirect them into a more positive direction (Zebrack & Chesler, 2001).

In the long run relationships may suffer as well. As any child grows older they start to develop and go through many changes. However, when diagnosed with cancer the child is not only faced with beating the disease, but also trying to balance the development of their sexuality. Olivo and Woolverton (2001) studied building blocks to healthy sexual behavior and how having cancer as a child affects adult sexuality. The building blocks studied included; physical functioning, the psychological development of the capacity for intimacy, and interpersonal functioning. All of these building blocks for healthy sexual behavior were impeded in survivors

of childhood cancer. Some survivors felt that that it was easier to give up relationships than face embarrassing issues that they were left with after cancer, and did not want to engage in dating because they thought the chances they were going to be around for a while were slim. Survivors also indicated that physical appearance alterations due to cancer were unattractive to the opposite sex, survivors had a hard time forming relationships with people their age, and even if they did have friends their age they were still more attached to their parents.

Growing up and dealing with the development of sexuality is hard enough as a healthy individual, but when coupled with a diagnosis of cancer an individual is faced with a much greater obstacle. The feeling of embarrassment, possible loss of fertility, and feeling 'different' than peers all have an effect on adult survivors of childhood cancer. Long-term survival was not thought about in the past because surviving childhood cancer was not likely. A long-term survivor of childhood cancer is someone that was diagnosed under the age of 18 and has been cancer free for five years. Forsbach and Thompson (2003) recognized that advancements in medicine and technology have given children a greater chance of survival when diagnosed with cancer, but once they become survivors have many challenges to face. Fear of relapse, cognitive and physical effects from treatments, as well as long-term effects from the cancer can all affect interpersonal relationships as an adult. These fears are not without warrant, survivors of childhood cancer have a 17.6% risk of developing another cancer after 15 years of being cured the first time, and the risk gets higher after 25 years (Forsbach & Thompson, 2003). Although medical advancements have prolonged the life of children diagnosed with cancer, the long term negative effect of quality of life of these individuals was not recognized. There were 111 participants that voluntarily took a survey from a cancer survivor website and the researchers found that their findings were similar to those of past research regarding interpersonal

relationships of adult survivors which leads to increased validity (Forsbach & Thompson, 2003). This study supported many facts that were found in earlier research, such as most childhood cancer survivors have some physical effects from the chemotherapy treatment, fertility issues, concern of passing on the disease to their children, and job discrimination. All of these issues are related to forming relationships later in life. Age of diagnosis was associated more closely with relationships with peers, meaning that the older the child was the harder it was to develop relationships because they had a harder time accepting the scars from treatment than younger children. Amount of time spent in a hospital and receiving treatment had a negative effect on sibling relationships, possibly because the patient was taking away family time from the other siblings, while fear of relapse had a negative impact on intimate relationships (Forsbach & Thompson, 2003).

However, the patients are not the only ones left with side effects from their cancer treatment and remission; often their families are indirectly affected by the cancer diagnosis as well. Chemotherapy, radiation therapy, surgery, or a combination of a few of these treatments gives a child a much greater chance at survival than a few decades ago, but these treatments are often seen as worse than the disease itself. Brown, Madan-Swain, and Lambert (2003) conducted a study to determine if posttraumatic stress symptoms were significant in the survivors and their mothers. Participants completed both the patient and parent measures and Brown et al. (2003) found that the adolescent cancer survivors were more likely to report more stressful life events and have a greater number of posttraumatic stress disorder (PTSD) symptoms than their healthy counterparts. The same was true for the mothers of survivors versus the mothers of the healthy comparison group. Mothers of cancer survivors that had a good support system had fewer PTSD symptoms while cancer survivors with reportedly less social

desirability had more PTSD symptoms. Intervention programs focused on lessening the PTSD symptoms in both the cancer survivor as well as their mothers will lead to a better quality of life for the family. While adult survivors are dealing with many issues stemming from their battle with cancer their families, most notably their mothers, are also dealing with issues as well.

Children are surviving cancer more than ever even though incidence rates are high. However, these new survivors of childhood cancer are not impervious to future diagnoses. Their lives will always be affected by the cancer from their childhood in some way. Some survivors have a hard time forming meaningful relationships, others experience symptoms of PTSD, and still others have to deal with trying to come to terms with their sexuality. In the long-term, childhood cancer does not end with remission. Scars, feelings of self-doubt, and low self-esteem often plague many survivors into adulthood. While medical advancement has reduced the mortality rate in children diagnosed with cancer, their lives after cancer are greatly affected. Risks of cancer as well as preventive measures are imperative to protect this group. We cannot protect the children if we do not know what is causing the disease. At the same time if we are able to protect more children from this disease we will not have to address the challenges that appear later in life because they will not be present in the first place. Studying the OCISS data may offer insight to clinicians, public health personnel, as well as parents.

Methods

A descriptive study was conducted using data from the Ohio Cancer Incidence Surveillance System (OCISS) database, (Ohio Department of Health, 2010) 1996-2011. The data was previously collected, is de-identified, and the faculty advisor that will oversee this project has permission to work with the OCISS data. Institutional Review Board (IRB) approval was requested at Wright State University and received.

Using the OCISS data, a descriptive analysis of childhood cancer was conducted examining incidence and mortality rates among childhood cancer patients, number of children in Montgomery County diagnosed with childhood cancer by race and sex, and primary insurance at time of diagnosis. Incidence rates, mortality rates, and types of cancer were then compared to Ohio and United States statistics using publically available datasets. For comparison to the United States and Ohio, years 1999-2009 were available. Variables considered include, but are not limited to, age, sex, race, primary insurance, and vital status. Publically available datasets used were accessed through CDC Wonder incidence rates (USDHHS, CDC, & NCI, 2011), CDC Wonder mortality rates (USDHHS, CDC, & NCI, 2008), National Cancer Institute (2008), population data for the United States from United States Census Bureau (United States Census Bureau, 2011b), and population data for Ohio and Montgomery County from United States Census Bureau (United States Census Bureau, 2011a).

Results

Table 1 shows the percentages of children that have cancer broken down by race and sex. Of children with cancer in Montgomery County, Table 1 shows that there is a higher proportion of black children with cancer than Ohio and the United States. The data set shown in Table 1 represents data taken between 1999 and 2009 (USDHHS, CDC, & NCI, 2011; Ohio Department of Health, 2010).

Table 1

Children with Cancer (<1-19 years old), by Race and Sex 1999-2009

Category	United States	Ohio	Montgomery County
White Male	87.31%	88.15%	79.29%
Black Male	12.69%	11.85%	20.71%
White Female	86.58%	87.71%	79.84%
Black Female	13.42%	12.29%	20.16%

Of children with cancer, the breakdown between races is shown in Figure 1, Figure 2, and Figure 3. Figure 1 shows the breakdown for the United States from the CDC Wonder database (USDHHS, CDC, & NCI, 2011), Figure 2 represents the breakdown for Ohio from the CDC Wonder database (USDHHS, CDC, & NCI, 2011), and Figure 3 presents the breakdown between races in Montgomery County (Ohio Department of Health, 2010).

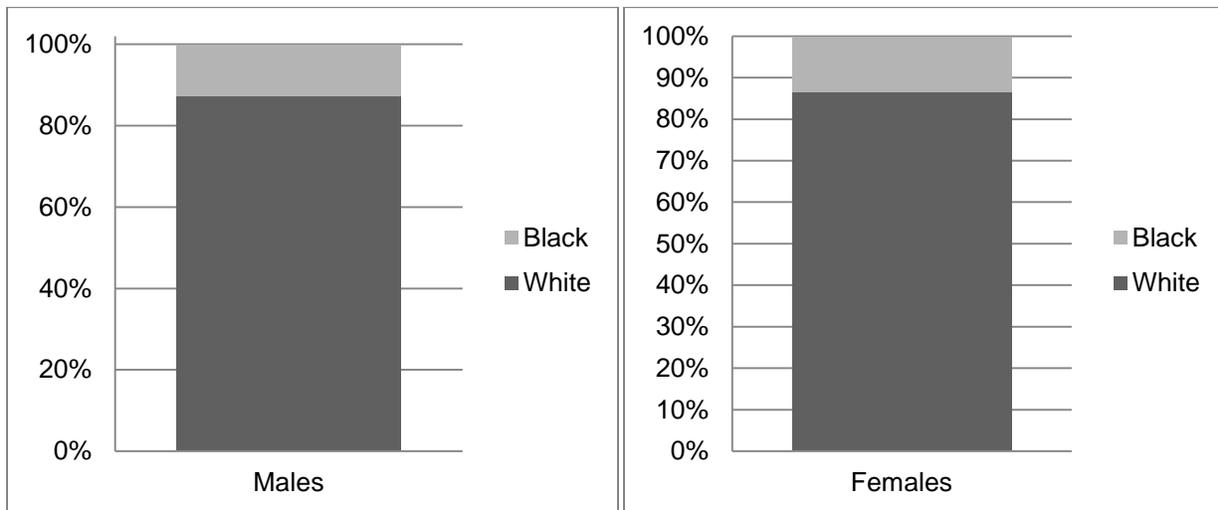


Figure 1. White versus black (male / female) proportions of childhood cancer (ages <1-19) in the United States, 1999-2009

Childhood cancer proportions by race in the United States follow the population breakdowns of the United States. The population of the United States is comprised of about 78% whites and 13% blacks (United States Census Bureau, 2011b). This means there are about six

times more whites than there are blacks in the United States. This data also reflects that there are at least six times more cases of white children with cancer versus black children with cancer.

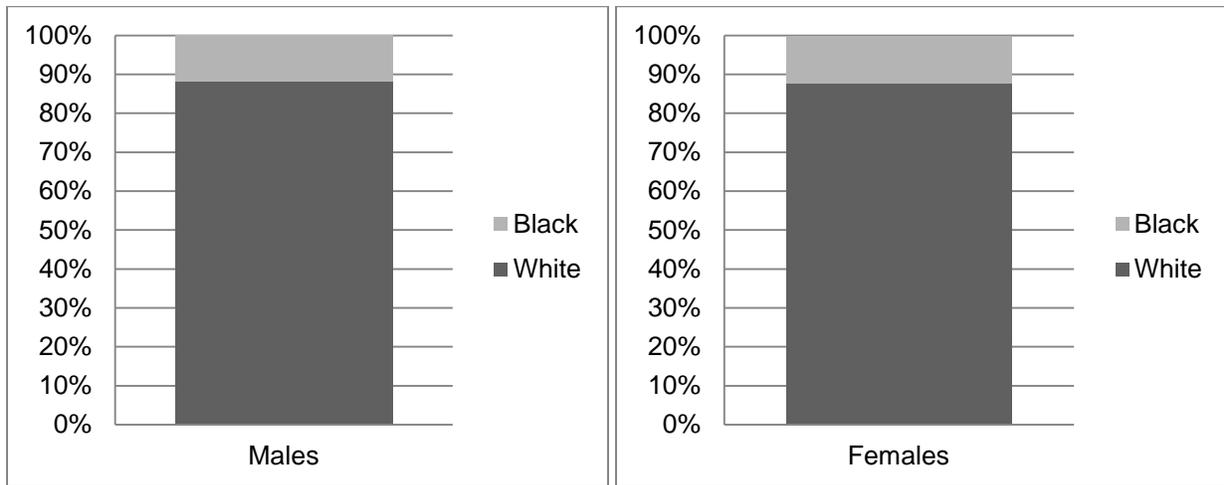


Figure 2. White versus black (male / female) proportions of childhood cancer (ages <1-19) in the Ohio, 1999-2009

Childhood cancer proportions in Ohio follow the population breakdown of Ohio as well. Ohio is made up of about 84% whites and about 12% blacks (United States Census Bureau, 2011a). There are about seven times more whites than there are blacks in Ohio. The data collected reflects that there are at least seven times more white children with cancer versus black children with cancer. The data for the year 2000 were suppressed because of low incidences of cancer for black females. Since 2000 only had partial data available from CDC Wonder, it was not included so that there would not be a skewed proportion of black females with cancer and white females with cancer.

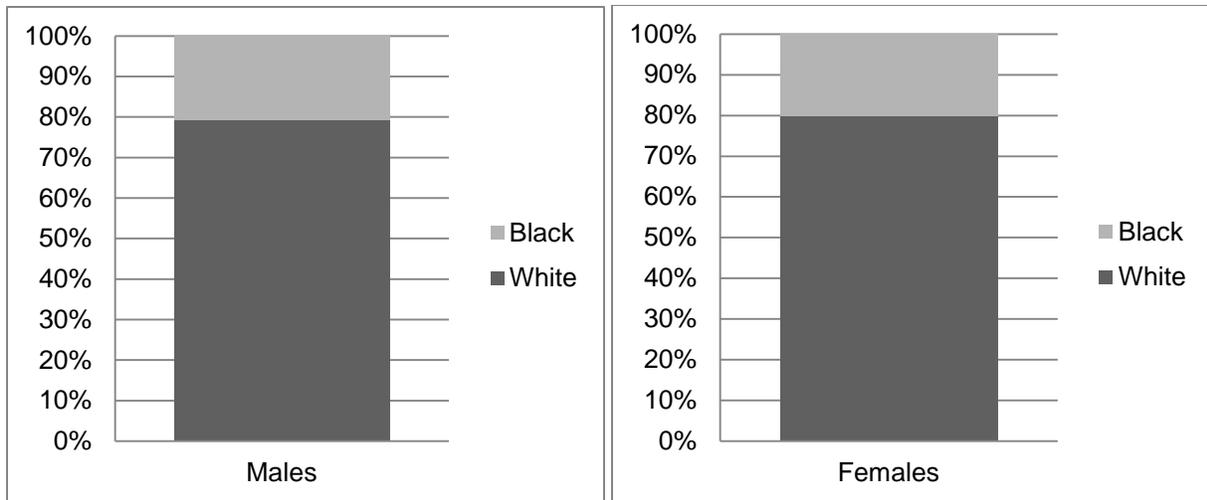


Figure 3. White versus black (male / female) proportions of childhood cancer (ages <1-19) in Montgomery County, 1999-2009

Childhood cancer proportions in Montgomery County also follow the population tendencies in Montgomery. Montgomery County is comprised of about 74% whites and 21% blacks (United States Census Bureau, 2011a). This reflects that there is about one-fifth the numbers of black children as white children. The data reflects that trend as well, about one-fifth of the cases of childhood cancer are attributed to black children.

Table 2 shows the incidence rates of childhood cancer for all races, ages <1-19 years old for the United States (USDHHS, CDC, & NCI, 2011), Ohio (USDHHS, CDC, & NCI, 2011), and Montgomery County (Ohio Department of Health, 2010). Since the number of incidences of childhood cancer is small in Montgomery County, the data for Montgomery County is quite variable, but the overall averages are similar in the United States, Ohio, and Montgomery County.

Table 2

Incidence Rates for Children (<1-19 years old) with Cancer, U.S., Ohio, and Montgomery County 1999-2009

Year	U.S.	Ohio	Montgomery County
1999	15.9	16.4	18.8
2000	16.3	14.9	16.9
2001	16.9	15.5	18.8
2002	16.9	16.0	13.6
2003	16.6	18.0	13.0
2004	17.3	17.7	20.8
2005	17.0	17.5	17.5
2006	17.1	17.1	22.1
2007	17.3	15.4	11.7
2008	17.4	17.1	18.8
2009	16.9	15.5	11.7
Average	16.9	16.5	16.7

Note. Incidence rates per 100,000.

Table 3 shows the childhood cancer mortality rates for the United States (USDHHS, CDC, & NCI, 2008), Ohio (USDHHS, CDC, & NCI, 2008), and Montgomery County (Ohio Department of Health, 2010). Since the mortality rates for childhood cancer produce small numbers, there is high annual variability in the Montgomery County data when compared to the United States and Ohio data. In 2001, the mortality rate in Montgomery County was more than two times the rate in the United States and Ohio, but the rate in 2005 was only 0.6, which is four times less than the other rates. In the end, however, the overall average mortality rates are similar for all years.

Table 3

Mortality Rates for Children (<1-19 years old) with Cancer, U.S., Ohio, and Montgomery County 1999-2005

Year	U.S.	Ohio	Montgomery County
1999	2.8	2.8	2.6
2000	2.8	3.2	3.9
2001	2.8	2.4	5.8
2002	2.8	2.6	1.3
2003	2.7	2.3	1.9
2004	2.7	2.5	1.9
2005	2.7	2.6	0.6
Average	2.8	2.6	2.6

Note. Mortality rates per 100,000.

Figure 4 through Figure 11 represent various characteristics for children with cancer in Montgomery County (Ohio Department of Health, 2010). Looking at the black and white populations of children with cancer in Montgomery County, Figure 4 through Figure 11 illustrate such characteristics as vital status, stage at diagnosis, and primary insurance at time of diagnosis.

The number of childhood cancer cases in Montgomery County from 1996-2011 was 472. According to the OCISS database the percent of children still living is 87%; while the percent deceased is 13%. This is not a 5-year survival rate; it reflects the most current data on the status of the patient. When vital status is compared there appears to be a disparity between races. In this data, blacks make up about 20% of the incidences of children with cancer, however, they account for almost 32% of the deceased population (Figure 4).

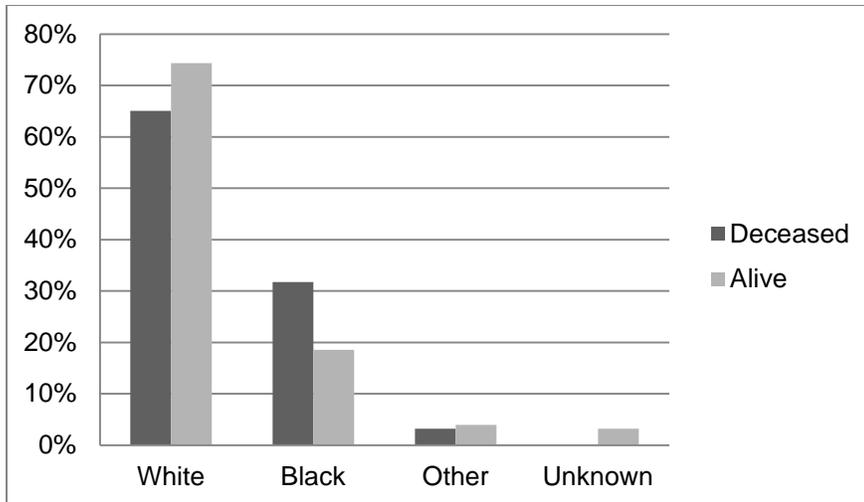


Figure 4. Children with cancer in Montgomery County, by vital status and race, 1996-2011, using data adapted from OCISS database

The OCISS database categorizes childhood cancer into three main diagnosis stages; early, late, and unstaged or unknown. Of all cases diagnosed in Montgomery County, 51% were diagnosed in the late stage from 1996-2011, compared to 36% diagnosed in the early stage (Figure 5).

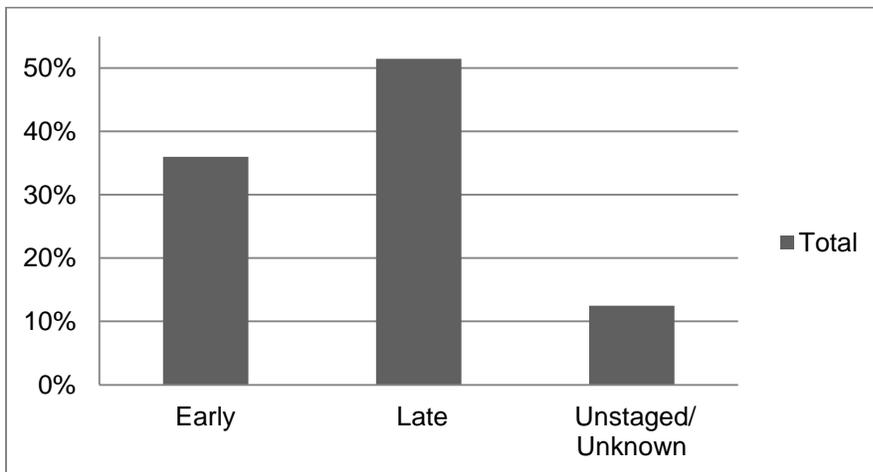


Figure 5. Childhood cancer by stage at diagnosis, Montgomery County, 1996-2011, using data adapted from OCISS database

Figure 6 illustrates the difference in vital status by stage at diagnosis. When diagnosed in the late stage 65.1% were deceased versus 23.8% deceased in an early stage diagnosis.

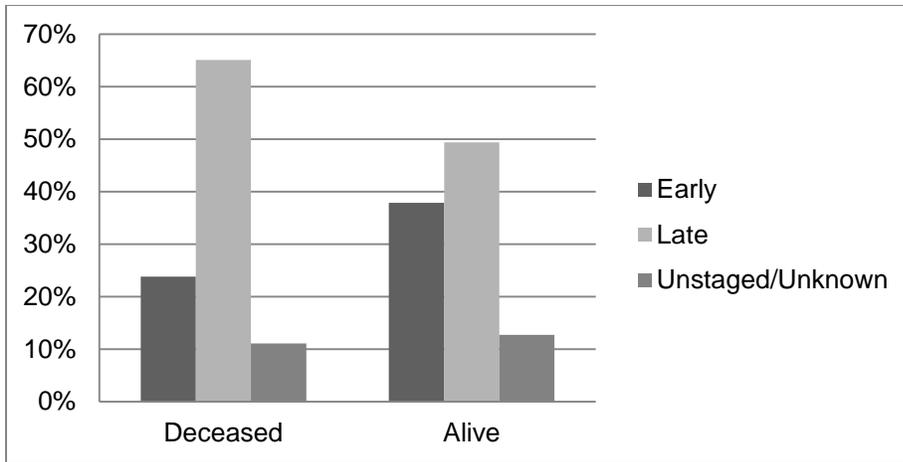


Figure 6. Vital status by stage at diagnosis, Montgomery County, 1996-2011, using data adapted from OCISS database

When the early and late stage percentages were compared, by race, to the total cases of cancer for each race the proportions were similar (Figure 7). Although there are many more white children with cancer, the rates of children that are being diagnosed early are similar between black children being diagnosed early and for late stage diagnoses.

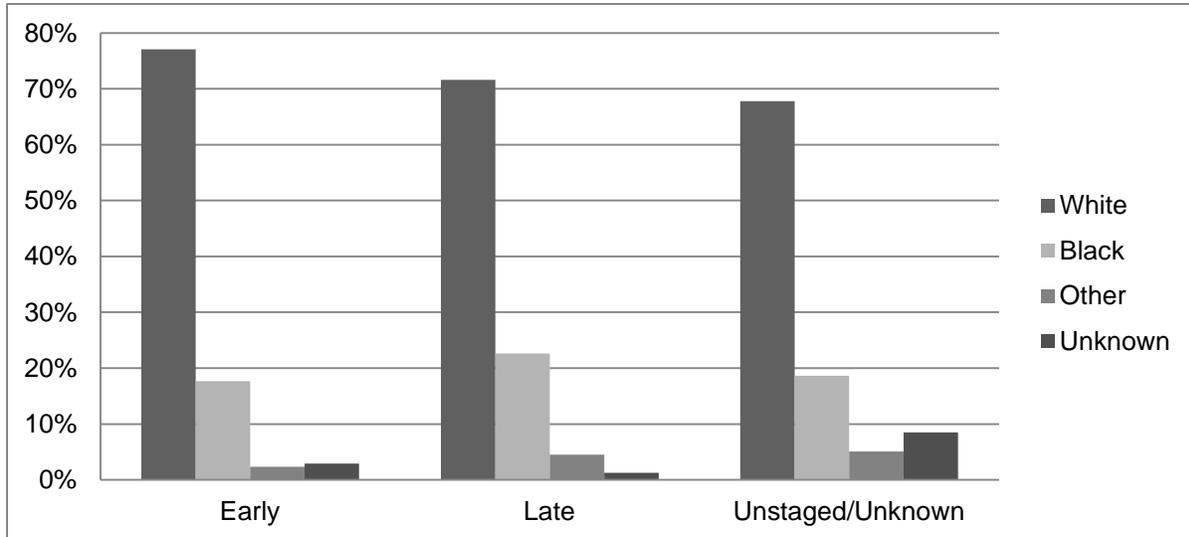


Figure 7. Race by stage at diagnosis, Montgomery County, 1996-2011, using data adapted from OCISS database

At the time of diagnosis, the primary payer for children in Montgomery County with cancer was private insurance, which accounted for more than 71% of total cases. Medicaid accounted for about 20% of the cases (Figure 8).

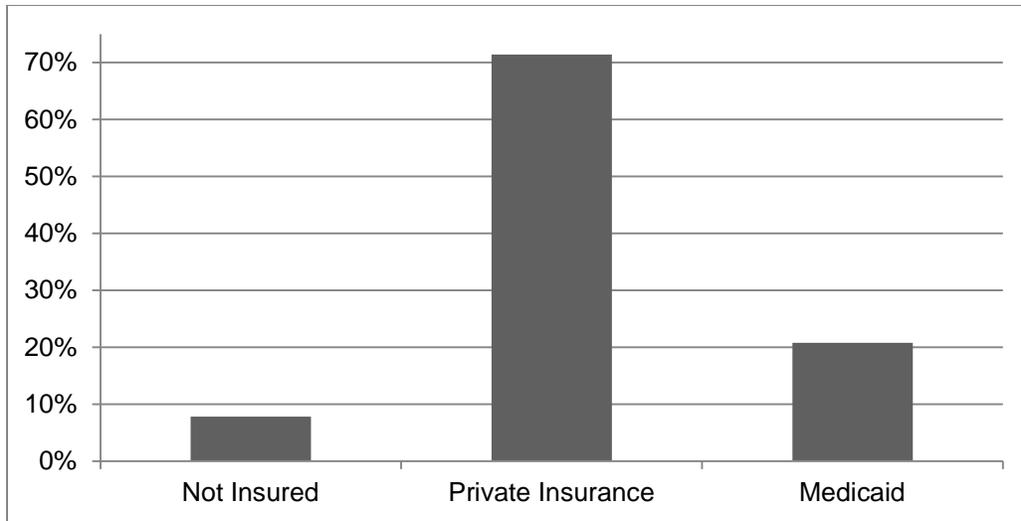


Figure 8. Insurance coverage at time of diagnosis, Montgomery County, 1996-2011, using data adapted from OCISS database

Figure 9 shows more closely the amount of children that had Medicaid as their primary payer at time of diagnosis. The number of patients that did not have Medicaid as their primary payer is almost 4 times higher than patients that did have Medicaid coverage.

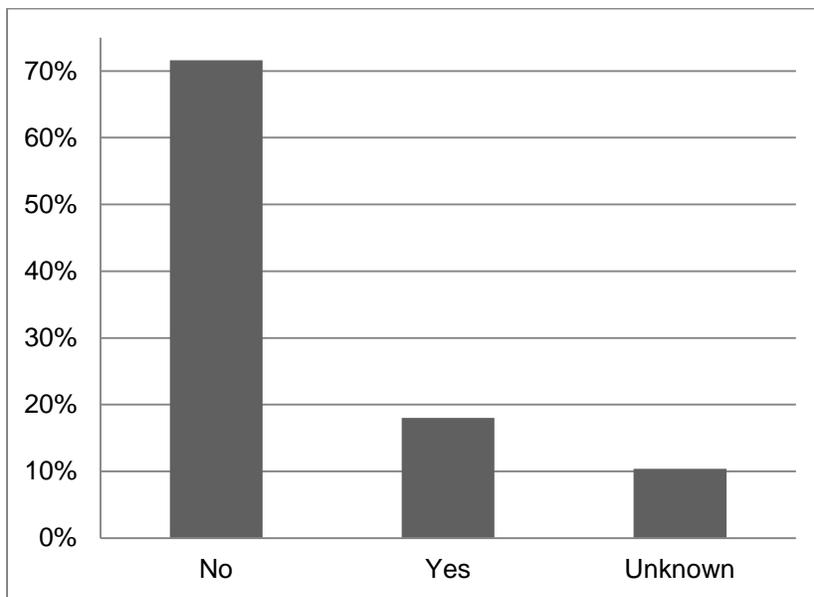


Figure 9. Medicaid coverage at time of diagnosis, Montgomery County, 1996-2011, using data adapted from OCISS database

The data indicates that whether or not the child had Medicaid coverage at time of diagnosis did not affect the vital status. When the patient did not have Medicaid the percent

deceased is 12.43%, while the percentage is 12.94% when the patient did have Medicaid coverage. The percentage of children still alive without Medicaid is 87.6% and the percentage with Medicaid still alive is 87.1% (Figure 10).

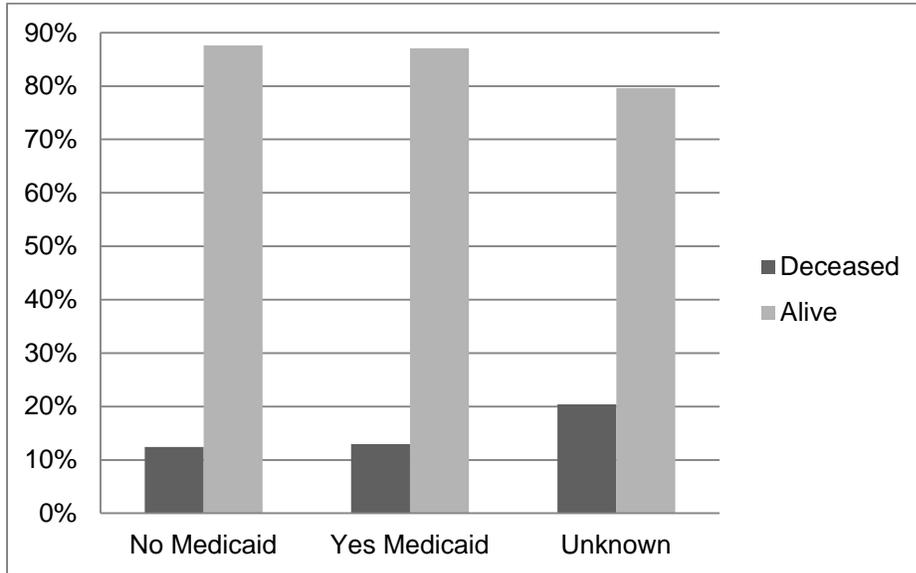


Figure 10. Medicaid coverage and vital status, Montgomery County, 1996-2011, using data adapted from OCISS database

The data reflects the percentage of stage at diagnosis by Medicaid coverage or other coverage. The percentage of late stage diagnosis with no Medicaid coverage is 53.6%, while the percentage of late stage diagnosis with Medicaid coverage is 54.1% (Figure 11).

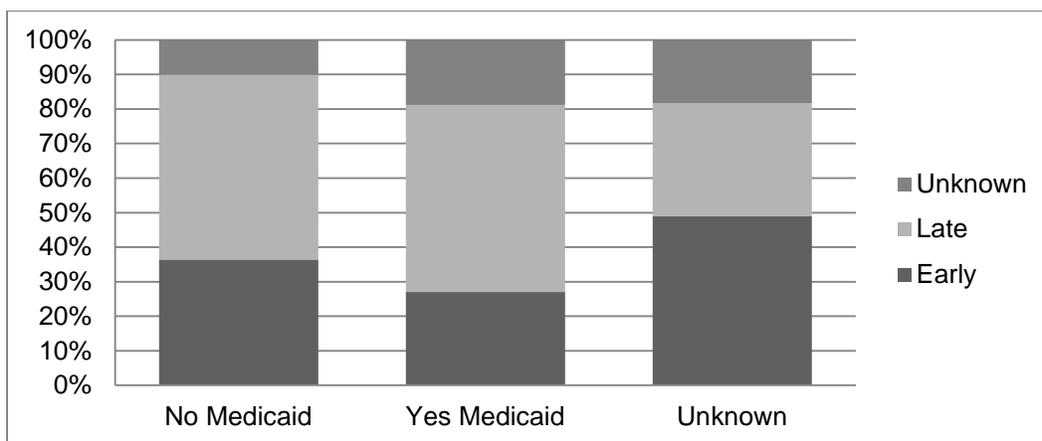


Figure 11. Medicaid coverage by stage at diagnosis, Montgomery County, 1996-2011, using data adapted from OCISS database

Discussion

Comparison of White vs Black Children with Cancer: U.S., Ohio, and Montgomery County

The trends for children with cancer follow the United States Census Bureau population percentages, however, for Montgomery County, more black children, in proportion with white children, are diagnosed with cancer compared to Ohio or the United States. In Ohio and the United States about 11-13% of the incidences of childhood cancer were attributed to black children, but in Montgomery County more than 20% of all cases were attributed to black children. This means that the number of black children diagnosed with cancer in Montgomery County is almost 7% higher overall than the comparative sites. This number, although higher, does not mean that more blacks, in proportion, are getting cancer, just that the total population of white versus black in Montgomery County is not the same as the United States or Ohio. Current research also shows that it is more likely for white children to develop cancer than other races, so these trends follow current National Cancer Institute (2008) data.

Incidence Rates and Mortality Rates

Incidence rates of childhood cancer throughout the United States, Ohio, and Montgomery County are all increasing as time progresses. This data does follow previous findings that incidence rates are on the rise for childhood cancer (National Cancer Institute, 2008). Studies are needed so implementation of evidence-based strategies can be used to combat rising incidence rates.

Mortality rates in the United States and Ohio were stable throughout the years of data collected; however Montgomery County data is much more variable with mortality rates. Some years the mortality rate is high, 2001 at 5.8, while other years the incidence is low at 0.6. This variation can be attributed to the low number of cases for childhood cancer in Montgomery

County. This data seems to be following current research of lower mortality rates (National Cancer Institute, 2008), but more years need to be studied for this data to be accepted as significant.

Vital Status

The incidences of childhood cancer are still on the rise; however mortality rates have notably decreased with medical advances. This means that more and more children are surviving childhood cancer than ever before. According to the National Cancer Institute (2008), the five-year survival rate is now up to 79%. The public health implications for these high survival rates can be seen in adult survivors and the obstacles they face in the future with relationships, self-esteem issues, PTSD, and other difficulties. With these new findings, it is important for public health to find ways to help these survivors with increased counseling and awareness of the possible future side effects.

Yet, vital status is another area where the black children in Montgomery County are not in proportion compared to the white children with cancer. Black children make up about 20% of all cases from 1996-2011, according to the OCISS database (Ohio Department of Health, 2010). However, they account for 32% of all patients deceased. This means that the number of deceased black children diagnosed with childhood cancer is over 60% higher than expected of black children diagnosed, when compared to all races. The proportion of black children alive after diagnosis is 18.6%, which is slightly lower than the 20% proportion. In comparison, white children diagnosed with cancer make up about 73% of the total population. The number of white children deceased is much lower than this proportion at 65%, and the number of white children alive is about the same proportion at 74%. These disproportionate numbers make it important

for public health to educate parents and guardians about childhood cancer and why early detection is important for long term survival.

Early and Late Stage Detection

The stage at which cancer is diagnosed is important because it affects the prognosis of the patient. Generally, if cancer is detected early, it is not as advanced and has not spread as much as cancer diagnosed in a later stage. This means that the early diagnosis is important for a better survival prognosis.

In Montgomery County 51% of the cancer cases are late stage diagnoses, while only 36% are early stage. As Figure 6 shows, children diagnosed in late stage had more than 2.5 times more cases deceased versus those diagnosed in an early stage. When looking at stage diagnosis by race the proportions follow the trends. There is not one race with more late diagnoses in proportion with another race in accordance with the overall relationship. When looking at the proportion of children with cancer in Montgomery County, the proportion that is white children is 73%. When looking at early diagnosis cases, white children make up 77%, and when looking at late diagnosis cases white children make up 71.6%. When compared to the population of children with cancer, the percentage that is black children with cancer in Montgomery County is 20%. When looking at early diagnosis cases, black children make up 17.7% and when looking at late stage diagnosis, black children make up 22.6%. Since current literature on childhood cancer is limited, it is not known why some of these disparities exist. However, it is important to try and educate all parents and guardians in the same manner. Early detection is important in the long term survival of a child with cancer.

Insurance as an Indicator of Poverty

When looking at primary payers at time of diagnosis, the overall majority had private insurance. Medicaid is generally seen as a predictor of poverty. To qualify for Medicaid for an adult or child is dependent on the family income. In Montgomery County, only 85 of the 423 childhood cancer cases had Medicaid as their primary insurance (18%). Medicaid turned out to be not substantial in predicting children that get cancer. More than 61% of the known primary payers were private insurances.

When other factors were considered in relation to Medicaid, there were no substantial findings. The percentage of cases with Medicaid that are deceased is 12.94%, while the percentage of cases without Medicare that are deceased is 12.43%. These percentages indicate that the difference in Medicaid payer and other payer is not considerable. Also, late stage diagnoses were also similar in percentage between Medicaid as payer, 54.12%, and other primary payer, 53.55%. Again, with the percentages so close in proportion to each other the findings on Medicaid coverage was not suggestive.

Limitations

Since childhood cancer statistics are based on small numbers, it is important to note the limitations for this study. CDC Wonder data (USDHHS, CDC, & NCI, 2008 & 2011), was used to compare data from the United States and Ohio with the OCISS dataset (Ohio Department of Health, 2010) for Montgomery County. The CDC Wonder dataset had suppressed data when the numbers were not high enough to report, so the only data that was usable was the childhood cancer statistics for white children and black children, and ages <1-19. This reduced the number of cases from the OCISS dataset to only include white children, black children, and eliminated the cases for children above the age of 19. The CDC Wonder database only had data for 1999-

2009, and 1999-2005, for mortality rates, so the OCISS data was condensed to reflect the same years. The cases excluded from the OCISS dataset to compare statistics with the United States and Ohio were added back in when calculating the additional information in this descriptive study. The Montgomery County data included figures from 1996-2011, but since the numbers for childhood cancer are limited the statistics were often grouped all together or grouped into 5-year increments in order to give more meaningful findings. Although other races, as well as unknown races, were noted in the graphs, the numbers were quite low, accounting for only 6.6% of the total number of cases, so the study focused more on the difference between white and black children, so that there were more cases making the totals more substantial.

Public Health Implications

Cancer, in any form, is a concern for the public's wellness. While many cancers have some known risk factors and protective factors, childhood cancer is unusual because the risk factors and preventive factors are generally unspecified. With the medical advancements keeping more childhood cancer patients alive well into their adult years the public health focus shifts to childhood cancer survivor issues. The difficulties that these survivors will encounter, such as poor outlook on life (Zebrack & Chesler, 2001), PTSD symptoms (Brown et al., 2003), difficulty forming health sexual behavior (Olivo & Woolverton, 2001), and forming relationships later in life (Forsbach & Thompson, 2003), need to be addressed by the patient, the physicians, and public health. This vulnerable population needs to be protected and public health can take a role in educating on the early warning signs of childhood cancer to increase early detection and better prognoses across the board. Education on proper pesticide use may also be useful since that is one of the few known risk factors and any education to the public is important if it will

protect a life. Since the research conducted on childhood cancer survivors is not definitive, trying to safeguard this population is essential.

Conclusions

The most worrisome statistic in this research is the fact that over half of the children in Montgomery County diagnosed with childhood cancer are at a late stage of cancer. This means that their prognosis is lessened right from the beginning. Many of the treatments and therapies that are available for children with cancer are invasive, harsh, and leave lasting scars, both physically and mentally. Even with an early stage diagnosis, these complications are still possible. However, if the cancer is not as advanced or spread as a late stage diagnosis the plan for treatment may not be as devastating to the child. While 86% of children in Montgomery County diagnosed with childhood cancer are still alive, the stronger therapies and treatments needed in the late stage may affect these children later in life. More research is being done on the long-term effects of childhood cancer because more children are surviving. However, the results from these studies are not positive and it's been shown that these survivors have more obstacles to overcome in their future relationships with themselves and others.

The discrepancy in the vital statistics also requires more research. The percentage of black children that are deceased is notably higher than the overall proportion of black children with cancer. Although the percentage of white children with cancer is much higher, their chances of survival are better than black children with cancer. In the end, this descriptive study shows that there needs to be more examination into why there are differences in the white and black childhood cancer population and what can be done to inform parents about the warning signs of childhood cancer.

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Appendix A: List Tier 1 Core Public Health Competencies Met

Domain #1: Analytic/Assessment
Identify the health status of populations and their related determinants of health and illness (e.g., factors contributing to health promotion and disease prevention, the quality, availability and use of health services)
Describe the characteristics of a population-based health problem (e.g., equity, social determinants, environment)
Use variables that measure public health conditions
Use methods and instruments for collecting valid and reliable quantitative and qualitative data
Identify sources of public health data and information
Recognize the integrity and comparability of data
Identify gaps in data sources
Adhere to ethical principles in the collection, maintenance, use, and dissemination of data and information
Domain #2: Policy Development and Program Planning
Gather information that will inform policy decisions (e.g., health, fiscal, administrative, legal, ethical, social, political)
Domain #3: Communication
Identify the health literacy of populations served
Communicate in writing and orally, in person, and through electronic means, with linguistic and cultural proficiency
Solicit community-based input from individuals and organizations
Domain #4: Cultural Competency
Incorporate strategies for interacting with persons from diverse backgrounds (e.g., cultural, socioeconomic, educational, racial, gender, age, ethnic, sexual orientation, professional, religious affiliation, mental and physical capabilities)
Recognize the role of cultural, social, and behavioral factors in the accessibility, availability, acceptability and delivery of public health services
Respond to diverse needs that are the result of cultural differences
Domain #5: Community Dimensions of Practice – N/A
Domain #6: Public Health Sciences
Describe the scientific evidence related to a public health issue, concern, or, intervention
Retrieve scientific evidence from a variety of text and electronic sources
Discuss the limitations of research findings (e.g., limitations of data sources, importance of observations and interrelationships)
Describe the laws, regulations, policies and procedures for the ethical conduct of research (e.g., patient confidentiality, human subject processes)
Domain #7: Financial Planning and Management – N/A
Domain #8: Leadership and Systems Thinking
Identify internal and external problems that may affect the delivery of Essential Public Health Services
Describe the impact of changes in the public health system, and larger social, political, economic environment on organizational practices