Introduction

The kidney is the site of approximately 7% of childhood malignancies including nephroblastoma (Wilms'tumor), clear cell sarcoma of the kidney (CCSK), malignant rhabdoid tumor (MRT), renal cell carcinoma (RCC), and congenital mesoblastic nephroma (CMN). Wilms'tumor is an exemplar for multimodal treatment of pediatric solid tumor. Improvements in surgical techniques and postoperative care, recognition of the sensitivity of Wilms'tumor to irradiation, and the availability of active chemotherapeutic agents have led to a dramatic change in the prognosis for this once uniformly lethal malignancy ***(Fernandez et al., 2016).***

Wilms'tumor (Nephroblastoma) is s a type of cancer that starts in the kidneys. It is the most common type of kidney cancer in children, named after Max Wilms, a German doctor who wrote one of the first medical articles about the disease in 1899 ***(American Cancer Society, 2014).***

Nephroblastoma (Wilms'tumor) is a malignant tumor that rises from metanephric mesoderm cell of the upper pole

of the kidney. It accounts for 20% of solid tumor in childhood, associated with congenital anomalies such as aniridia (lack of color in the iris), cryptorchidism, hypospadias, pseudo hermaphroditism, cystic kidney, hemangioma, and talipes disorder. Some children with disorder have a deletion on chromosome11. Without therapy, metastatic spread by bloodstream is most often to lung, regional lymph nodes, liver, bone, and eventually brain ***(Mclean & Castellino, 2008 and Pillitteri, 2010).***

Pediatric oncology nurses are essential contributors to the successful diagnosis, treatment, and cure of children with cancer. As a member of the multidisplinary care team, the nurse works with physicians, social workers, child life specialistis, psychologists, and other specialists to provide comprehensive care for the child and family. Innovative technologies require the nurses caring for children with cancer become experts in critical care management as well as in the provision of the psychological support to the child and family ***(Marilyn et al., 2016)***.

The expert oncology nurse often functions as the coordinator of the child care, facilitating communication among team members. Children are cared for by advanced

practice nurses in various patient care setting, including the hospital, out patient setting, and home environment ***(Marilyn et al., 2016).***

The nurse in this setting must have a support system, be aware of personal limitations and therapeutic relationship. Combines a love for children and the opportunity to be involved in scientific advances in the treatment of cancer. A career in pediatric oncology nursing is both challenging and rewarding ***(Greer and Williams, 2010).***

Nurses work with the Wilms'tumor children admitted to hospital should develop a close relationship with the children and their caregivers. They need to be closed with specialist team and share information to ensure that children and their caregivers receive optimal care during hospitalization and after discharge home ***(Valentine and Lowes, 2007).***

The caregiver is defined as the person who most often helps the child with cancer and the main (primary) caregiver is a spouse, partner, parent, or an adult child. When family is not around, close friends, co-workers, or neighbors may fill this role ***(Brown and Brown, 2014).***

Caregivers are the loved ones who give the children with cancer physical and emotional care. Caregivers may be partners, family members, or close friends. Most often, they are not trained for the caregiver's job. Many times, they are the lifeline of the children with cancer. Also the caregiver has a key role in the child's care. Good, reliable caregiver support is crucial to the physical and emotional well-being of children with cancer ***(Girgis et al., 2013).***

Significance of the study:

Wilms'tumor represents a large incidence among kidney tumors in young children. The child with Wilms' tumor may be exposed to many health problems due to the management with chemotherapy and radiotherapy. Therefore, the role of caregivers is important in maintaining the child's health ***(Hamilton et al., 2011).*** From this point the study was conducted to highlight the role of caregivers having children with Wilms'tumor accordingly, the based needs guidelines were developed by the researcher for them.

Aim of the Study

This study aimed to:

-Assess the role of caregivers having children with Wilms'tumor

-Design suggestion guidelines for caregivers having children with Wilms'tumor.

-Disseminate a guideline booklet for parent having children with Wilms'tumor based on need assessment.

Research Question:

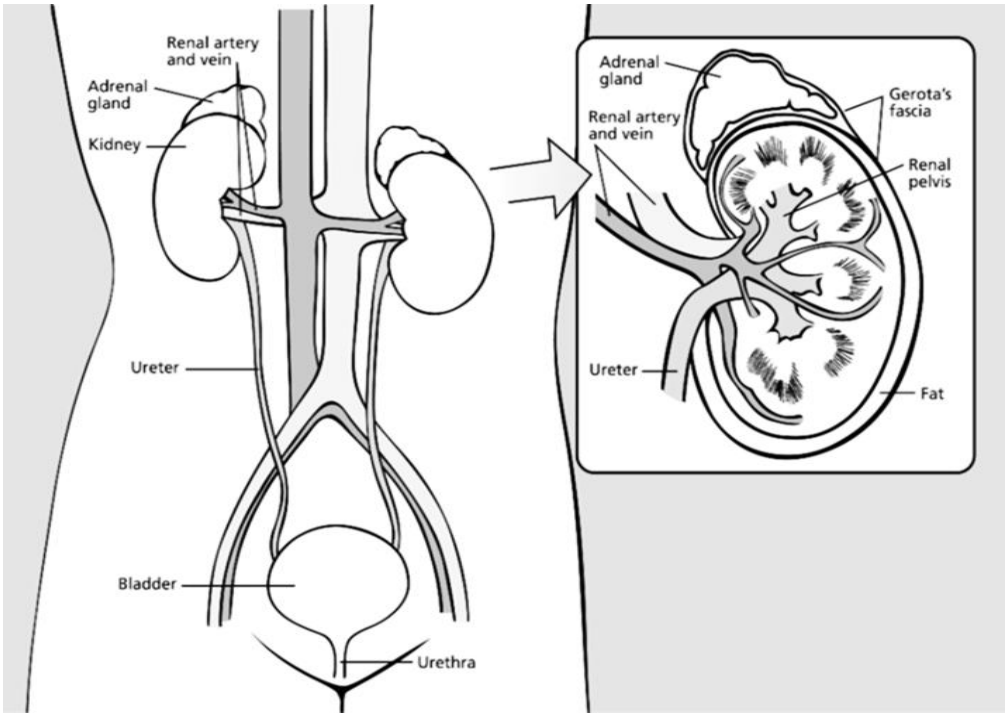
What is the role of caregivers having children with Wilms' tumor?

Review of Literature

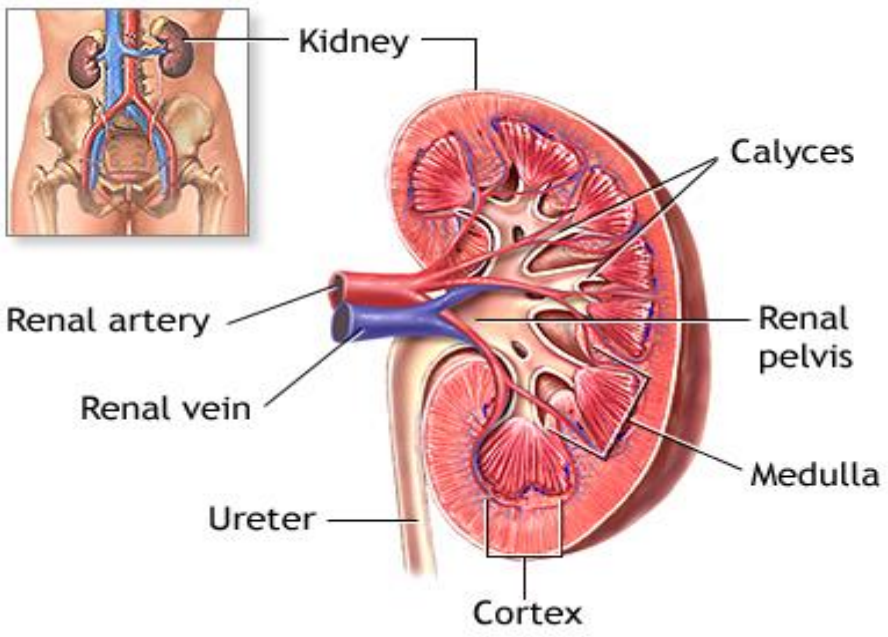
Overview about anatomy and physiology of kidney:

The kidneys are 2 bean-shaped organs that are attached to the back wall of the abdomen ***(fig.1&2*)**. Each kidney is about the size of a fist. One kidney is just to the left, the other just to the right of the backbone and the lower rib cage protects the kidneys ***(American Cancer Society, 2014).***

Figure (1): Anatomy of kidney.



Rosen, G. & Rosen, L. (2014): The kidneys are 2 bean-shaped organs that are attached to the back wall of the abdomen **(American Cancer Society, 2014).**



American Cancer Society. (2016): Cancer Facts & Figures 2016. Atlanta, Ga: American Cancer Society; 2016.

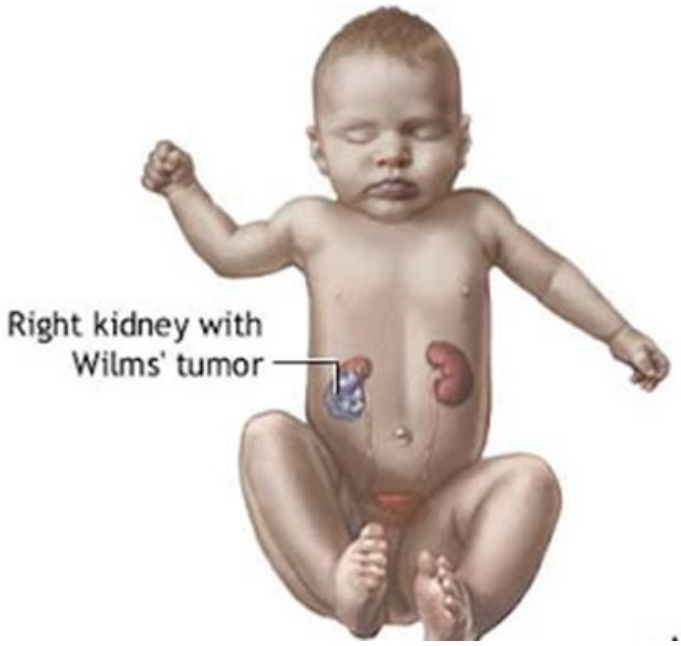
The kidneys are important for individuals the main function of kidney is to filter the blood, rid the body of excess water, salt, and waste products, this filtered products and extra water are changed into urine, the urine leaves the kidneys through long, slender tubes called ureters that connect to the bladder and urine flows down the ureters into the bladder, then stored there until the person urinates. Also from the kidney function it helps control blood pressure by making a hormone called renin, make sure that the body has enough red blood cells, by making ahormone called erythropoietin, which tells the bone marrow to make more red blood cells ***(Fernandez et al., 2011*)**.

Definition of Wilms'tumor:

Wilms'tumor or nephroblastoma is a highly malignant embryonal neoplasm that may involve one or both kidneys or is a common internal abdominal tumor of childhood and account for 6% of all childhood tumors ***(Sharma, 2013).***

Wilms'tumor is the most common renal tumor in children. Much research has been done on this disease, and the subsequent changes in the therapy have resulted in improved outcomes. Prognosis is related to stage of disease at diagnosis, histopathologic features of the tumor, and child's age ***(Anderson et al., 2011).***

Figure (2): RT Kidney with Wilms'Tumor.



American Cancer Society. (2016): Cancer Facts & Figures 2016. Atlanta, Ga: American Cancer Society; 2016.

Causes & Risk Factors:

Most Wilms'tumors have no clear cause, but there are some factors that affect risk such as: **Age**, Wilms'tumor is most common in young children, with the average age being about 3 to 4years, less common in older children, and rare in adults. **Race**, the risk of Wilms'tumor is slightly higher in African-American children than in white children and is lowest among Asian-American children; the reason for this is unknown. **Gender**, The risk of Wilms'tumor is slightly higher in girls than in boys. ***(American Cancer Society, 2009).***

Certain genetic syndromes/birth defects, there is a strong link between Wilms'tumor and certain kinds of birth defects, about 1 child to 10 with Wilms'tumor also has birth defects. Most birth defects linked to Wilms'tumor occur in syndromes. A syndrome is a group of symptoms, signs, malformations, or other abnormalities that occur together in the same person.Syndromes linked to Wilms'tumor include:

The syndrome of WAGR stands for the first letters of the physical and mental problems linked with this syndrome (although not all children have all of them): Wilms'tumor, Aniridia (complete or partial lack of the iris colored area of the eyes). Genitourinary tract abnormalities (defects of the kidneys, urinary tract, penis, scrotum, clitoris, testicles, or ovaries). Intellectual disability (Mental Retardation).

Children with this syndrome have about a 30% to 50% chance of having a Wilms'tumor. The cells in children with WAGR syndrome are missing part of chromosome 11, where the WT1gene is normally found, WAGR tend to get Wilms'tumors at an earlier age and often have bilateral disease (tumors in both kidney) ***(Green, 2013).***

The syndrome of Beckwith-Wiedemann: Children with this syndrome tend to be bigger than for their age, They have larger than normal internal organs, an enlarged tongue, an oversized arm and/or leg on one side of the body (hemihypertrophy), as well as other medical problems. They have about a 5% risk of having Wilms'tumors (or, less often, other cancers that develop during childhood), this syndrome is also caused by a defect in chromosome11 ***(Davidoff, 2013).***

The syndrome of Denys-Drash: This rare syndrome has been linked to changes (mutations) in the WT1 gene, in this syndrome the kidneys become diseased and stop working when the child is very young. Wilms'tumor usually develops in the diseased kidneys. The reproductive organs do not develop normally, which in boys may cause them to be mistaken for girls. Because the risk of Wilms'tumor is very high, the doctors often advise removing the kidneys soon after this syndrome is diagnosed ***(Dome et al., 2013).***

Other syndromes, less often of, Wilms'tumor has been linked to other syndromes including: Perlman syndrome, Sotos syndrome, Simpson-Golabi-Behmel syndrome, Bloom syndrome, E Li-Fraumeni syndrome, Frasier syndrome, Trisomy 18 ***(Astuti et al., 2012).***

Certain birth defects: Wilms'tumor is also more common in children with certain birth defects (without known syndromes): Aniridia (complete or partial lack of the iris colored area of the eyes). Hemihypertrophy (an oversized arm and/or leg on one side of the body). Cryptorchidism (failure of the testicles to descend into the scrotum) in boys. Hypospadias (defect in boys where the urinary opening is on the underside of the penis) ***(Wang et al., 2011).***

-Etiology:

Most Wilms'tumors occur in children with no unusual physical features and no family history of the disease. These are considered "sporadic" cases, approximately 1% to 2% of children with this disease, there is a genetic predisposition and familial occurrence, certain genes for Wilms'tumor have been identified. Wilms'tumor can occur in one or both kidneys; bilateral disease is more common in familial cases than in sporadic cases, which unknown causes, it has been associated with a variety of childhood syndromes and

congenital anomalies including aniridia, hemi hypertrophy, cryptorchidism, and hypospadias ***(Anderson et al., 2011).***

-Incidence:

Wilms'tumor is the most common renal malignancy in children with approximately 500 new cases diagnosed in the United States each year ***(Howlader et al., 2015).***

According to The Research Department at Cancer Children Hospital 57357 in Egypt (2015) reported that, the total children with Wilms'tumor enrolled from July 2007 till the end of 2015 was 574 children ***(Cancer registry-research department, 2015).***

Wilms'tumors are a cancers in children that can start anywhere in the kidneys, most Wilms'tumors are a unilateral, which means they affect only one kidney, and only one tumor, but 5% to 10% of children with Wilms'tumors have more than one tumor in the same kidney. About 5% of children with Wilms'tumors have bilateral disease (cancer in both kidneys).Wilms'tumors often become quite large before they are noticed. The average newly found Wilms'tumor is many times larger than the kidney in which it developed. Most tumors are found before they have spread (metastasized) to other organs. Even though doctors may think a child has a cancer such as Wilms'tumor based on a

physical exam or imaging tests, they cannot be certain until a sample of the tumor is looked at under a microscope; there is no increased incidence based on sex or race ***(American Cancer Society, 2016***).

-Epidemiology:

The incidence of renal tumors in the United States is 7.1 cases per million children under age 15 years. The total national incidence has been estimated at 600 cases per year on the basis of enrollment on the current Children's Oncology Group (COG) renal tumor biology and classification study. The vast majority of pediatric renal tumors are Wilms'tumor, but (RCC) surpasses WT as the most common renal malignancy in the 15-19 year age group ***(Fernandez et al., 2016).***

The incidence rate for Wilms'tumor is slightly higher for black populations, but substantially lower in Asians. The male: female ratio is (0.92: 1.00) for those with unilateral disease and 0.60: 1.00 for those with bilateral disease ***(Fernandez et al., 2016).***

The tumor presents at an earlier age among boys, with the mean age at diagnosis for those with unilateral disease being 41.5 months compared with 46.9 months among girls. The mean age at diagnosis for those who present with

bilateral disease is 29.5 months for boys and 32.6 month for girls ***(Fernandez et al., 2016).***

A recent systematic review of 37 studies found significantly increased risk of Wilms'tumor with antenatal maternal exposure to pesticides, high birth weight, and preterm birth ***(Fernandez et al., 2016).***

In the United States, the annual incidence of renal tumors is about seven cases per million children younger than 15 years, accounting for five percent of all childhood malignancies **(table 1)** and approximately 500 new cases per year. Wilms'tumor is the most common renal malignancy in children <15 years old, accounting for about 95 percent of all cases. In contrast, renal cell carcinoma is more common in the 15 to 19-year-old age group. In the United States, two-thirds of cases of Wilms'tumor are diagnosed before five years of age, and 95 percent before 10 years of age. In children with unilateral involvement, (the median age at diagnosis is 43 months in girls and 37 months in boys). Children with bilateral disease are diagnosed at an earlier age (median age, girls at 31 months and boys at 24 months. ***(Surveillance, Epidemiology, and End Results (SEER), 2015).***