

THE EPIDEMIOLOGY OF PEDIATRIC CANCER IN THE PALLIATIVE CARE UNIT AT DR. SOETOMO GENERAL HOSPITAL, SURABAYA

Epidemiologi Kanker Pada Anak di Instalasi Paliatif Rumah Sakit Umum Daerah Dr. Soetomo, Surabaya

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ARTICLE INFO

Article History:

Received January, 8th, 2019

Revised form April, 16th, 2019

Accepted January, 17th, 2020

Published online January, 28th, 2020

Keywords:

epidemiology;
cancer;
children;
palliative

Kata Kunci:

epidemiologi;
kanker;
anak;
paliatif

ABSTRACT

Background: Children with cancer require special interventions and palliative care to improve their quality of life. The epidemiology of pediatric cancer is needed as a basis for determining health policy. **Purpose:** This study describes pediatric cancer patients in the palliative outpatient clinic in Dr. Soetomo General Hospital, Surabaya. **Methods:** This study is an observational descriptive study that uses the medical records of pediatric patients with cancer at the palliative care unit in Dr. Soetomo General Hospital between June 2014 and July 2015. The data included the demographic characteristics of the pediatric cancer patients and was analyzed using descriptive statistics. **Results:** The number of children in the 1–5 years, 6–10 years, and 11–15 years age groups was similar, while noticeably fewer children fell into the 16–18 years group. The majority of children suffering from cancer were male (68,70%). The most common type of cancer in was blood cancer (leukemia) with a percentage of 51.91%, while the rarest types were retinoblastoma and lymph node cancer (malignant lymphoma) with percentage of 3.05%. **Conclusion:** The incidence of pediatric cancer patients in the palliative outpatient clinic was quite high. These patients tended to be male, aged 6–10 years, and suffered from leukemia.

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ABSTRAK

Latar belakang: Penyakit dan kondisi anak dengan kanker membutuhkan intervensi khusus yaitu perawatan paliatif untuk meningkatkan kualitas hidup anak. Data epidemiologi kanker anak diperlukan sebagai dasar penentuan kebijakan kesehatan. **Tujuan:** Penelitian ini bertujuan untuk mengetahui gambaran epidemiologi pasien kanker anak di Poli Paliatif dan Bebas Nyeri RSUD Dr. Soetomo, Surabaya. **Metode:** Penelitian ini merupakan penelitian observasional deskriptif dengan menggunakan data rekam medis pasien kanker anak di Rumah Sakit Umum Daerah (RSUD) Dr. Soetomo selama periode Juni 2014 – Juli 2015. Data yang diteliti

How to Cite (APA): Fithriyah, I., Konginan, A., Mahajudin M. S., Maramis, M. M., & Margono, H. M. (2020). The epidemiology of pediatric cancer in palliative care unit, Dr. Soetomo General Hospital, Surabaya. *Jurnal Berkala Epidemiologi*, 8(1), 65-71. <https://dx.doi.org/10.20473/jbe.v8i12020.65-71>

adalah karakteristik demografis pasien kanker anak di poli paliatif dan bebas nyeri. Data diolah dengan menggunakan statistik distribusi. **Hasil:** Jumlah anak dengan kanker yang dikonsulkan ke poli paliatif dan bebas nyeri RSUD Dr. Soetomo adalah sebanyak 131 anak. Proporsi terbanyak anak dengan kanker di poli paliatif dan bebas nyeri RSUD Dr. Soetomo yang berusia 6-10 tahun sebanyak 34% dan jenis kelamin terbanyak adalah laki-laki 69%. Jenis kanker yang paling umum adalah kanker darah (leukemia) dengan persentase 51,91%, sedangkan jenis yang paling jarang adalah kanker retinoblastoma dan kanker kelenjar getah bening (lymphoma maligna) dengan persentase 3,05%. **Kesimpulan:** Prevalensi kanker anak di Poli Paliatif dan Bebas Nyeri cukup tinggi. Jumlah proporsi terbanyak adalah anak laki-laki dan kelompok usia 6-10 tahun. Jenis kanker pada anak yang terbanyak adalah leukemia.

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INTRODUCTION

The worldwide incidence of cancer increases each year. According to the World Health Organization, there were 18.1 million new cases of cancer and 9.6 million deaths from cancer in 2018. The total number of people living with cancer for five years was estimated at 43.80 million (International Agency for Research on Cancer, 2018). The incidence of cancer in 2001–2010 in children aged 0–14 years was 140.60 per one million people per year and 155.80 per one million people per year for children aged 0–19 years (Steliarova-Foucher et al., 2017). A family history of cancer increases the risk of cancer occurring in children, while children with cancer are at risk of their cancer returning and also suffer from a decrease in bodily functions even after they are cured. Therefore, long-term care for pediatric cancer patients is needed (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Cancer is a cause of death in countries with low and high income levels (Torre, Siegel, Ward, & Jemal, 2016). Pediatric cancer is also the second highest cause of death after accidents in children aged 4–15 years (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014).

Pediatric palliative care refers to the care of a child's body, mind, and spirit and also involves providing support to the family. Effective palliative care requires a broad multidisciplinary approach that includes the child's family and all the available community resources (van der Geest, van der Heide, Pieters, Darlington, & van den Heuvel-Eibrink, 2016). The children who need palliative care are those with cancer, heart disease,

cirrhosis of the liver, congenital anomalies, endocrine disorders, HIV and AIDS, meningitis, kidney disease, neurological disorders, neonatal conditions, and/or drug-resistant tuberculosis. Palliative care in children is expected to improve their quality of life and positively affect the course of the disease (Connor et al., 2014).

Since 1980, the prevalence of pediatric cancer has increased from 124 per one million per year to 140.6 per one million per year. In Southeast Asia between 2001 and 2010, the total number of cancer cases was 12,251 out of 105,673,000 children and adolescents aged 0–19 years, with leukemia recorded as the most common type (52.70%). Data on the prevalence of pediatric cancer globally is not yet easily available, and the number of children suffering from cancer in low and middle income countries is not well recorded. Global research conducted on 532 cancer data collection agencies in 62 countries during 2001–2010 showed that the number of cancer incidents was 385,509 cases in children aged 0–19 years. The world cancer incidence ratio was 140.6 per one million children aged 0–14 years. The majority of cases involved leukemia, followed by central nervous system tumors and lymphomas (Steliarova-Foucher et al., 2017).

Cancer is yet to be widely studied in Indonesia, and the only available data refers to the cancer prevalence in Indonesia in 2013, which was 1.40:1,000. Therefore, this study looks at the basic data regarding palliative care in pediatric cancer in Dr. Soetomo Regional Hospital, Surabaya. This data will be the basis for policy makers in the future and will hopefully help to improve the quality of life of children with cancer. This study

aims to identify basic data on pediatric cancer patients in the Palliative Care Unit Dr. Soetomo General Hospital, Surabaya.

METHODS

This research was an observational descriptive study conducted at the Palliative Care Unit Dr. Soetomo General Hospital Surabaya. The research data was taken from the medical records of pediatric cancer patients in the Palliative Care Unit Dr. Soetomo General Hospital for a period of one year, from July 2014 to June 2015.

The variables examined in this study were demographic data, that are child age group, sex, and type of cancer in pediatric cancer patients in the Palliative Care Unit Dr. Soetomo General Hospital, Surabaya. Pediatric cancer patients are all patients who have been diagnosed with cancer in the age range 0-18 years who undergo treatment in palliative care unit, both from pediatric inpatients and palliative outpatients clinic, Dr. Soetomo General Hospital, Surabaya. The samples in this study were 131 pediatric patients with cancer diagnoses who were treated at the Palliative Care Unit, Dr. Soetomo General

Hospital, Surabaya. Data was analyzed using descriptive statistics.

RESULTS

Characteristics of pediatric cancer patients in the Palliative Care Unit at Dr. Soetomo General Hospital, Surabaya

The distribution of children treated in palliative care unit Dr. Soetomo General Hospital varies considerably. The number of children in the 1–5 years, 6–10 years, and 11–15 years age groups was similar, while noticeably fewer children fell into the 16–18 years group (4.59%) The majority of children suffering from cancer were male (68,70%) (Table 1).

The most common type of cancer in was blood cancer (leukemia) with a percentage of 51.91%, while the rarest types were retinoblastoma and lymph node cancer (malignant lymphoma) with percentage of 3.05%. Another cancer that have been treated in Palliative Care Unit are osteosarcoma, abdominal tumor, hepatoma, neuroblastoma, and nasopharyngeal carcinoma. (Table 1).

Table 1

Characteristics of pediatric cancer patients in the Palliative Care Unit at Dr. Soetomo General Hospital, Surabaya.

Category	Percentage	
	n	%
Age (years old)		
1 – 5	37	28.24
6 – 10	45	34.35
11 – 15	43	32.82
16 – 18	6	4.59
Sex		
Male	90	68.70
Female	41	31.30
Type of cancer		
Leukemia	68	51.91
Osteosarcoma	8	6.11
Abdominal Tumor	6	4.58
Hepatoma	5	3.82
Neuroblastoma	5	3.82
Nasopharyngeal Cancer	5	3.82
Retinoblastoma	4	3.05
Lymphoma Maligna	4	3.05
Others	26	19.84
Total	131	100.00

DISCUSSION

Pediatric cancer can affect children's quality of life, and pediatric cancer therapy can be a challenge for clinicians as the children may not fully understand their condition. This type of therapy also requires different interventions in terms of psychological development and family roles (International Agency for Research on Cancer, 2017; Kazak & Noll, 2015).

The external causes of pediatric cancer include birth weight, age, and congenital abnormalities, and the contribution of genetic variations is the focus of research by experts. Rare variations and non-Mendelian inheritance, such as maternal genetic effects or germline de novo mutations, also contribute to the risk of cancer in children (Spector, Pankratz, & Marcotte, 2015). A representative proportion of the global population requires high quality information about cancer incidence. It is needed to predict the prevalence of cancer in children in the future (International Agency for Research on Cancer, 2017).

Age Group of Pediatric Cancer Patients

The majority of children suffering from cancer in Surabaya are aged 6–10 years or 11–15 years. Data from collaborative research from various countries has stated that the highest percentage of pediatric cancer is found in children aged 0–4 years (Steliarova-Foucher et al., 2017). According to data from the Childhood Cancer Registry of Piedmont (CCRP), 24.70% of children aged 5–9, 30% of children aged 1–4 years, 7.50% of children under 1 year, and 12% of adolescents aged 15–19 years have cancer (Isaevska et al., 2017). Similarly, data from Switzerland has shown that highest prevalence of pediatric cancer was in children aged 1–4 years (36%), followed by children aged 5–9 years and children aged 10–14 years (Swiss Childhood Cancer Registry, 2011).

Data from the United States of America shows that the most proportion of the age group that has cancer is 0–14 years. It's suggests that twice as many children aged 0–14 years have cancer compared to adolescents aged 15–19 years (Zhu, Pickle, Zou, & Cucinelli, 2014), while data from Egypt has shown that 44% of children aged 0–4 years have cancer, followed by 26% of children aged 9–15 years and 22% of children aged 5–8 years (Malla, 2017). Research in North West Iran indicates that the highest prevalence of cancer occurs in children aged 0–4 years, while in North East Iran, the highest prevalence is in children aged 3–6 years (Fathi, Bahadoram, &

Amani, 2015). The research from other Asian countries, Japan, also shows that the highest age group suffering from cancer is the age group of 0–4 years (Katanoda et al., 2017). In contrast, research from New Zealand states that the prevalence is similar across age groups (National Child Cancer Network, 2010).

Research in China has shown that the majority of children with cancer are aged 0–5 years (57.14%) (Zheng et al., 2015), while results from Korea between 1999 and 2011 suggest that the highest prevalence is in children aged 10–14 years (32.20%) (Park et al., 2016). Research in Pakistan as a developing country shows that the most common age group to suffer from cancer is 5–9 years, with minimal differences between the other age groups (Badar & Mahmood, 2017). In contrast, research carried out in Thailand between 1985 and 2009 found that the age group most likely to have pediatric cancer was 0–4 years (Wiangnon, Jetsrisuparb, Komvilaisak, & Suwanrungruang, 2014), and research carried out in 1993–2012 in Northeast Thailand found the same (Wongmeerit, Suwanrungruang, Jetsrisuparb, Komvilaisak, & Wiangnon, 2016).

The prevalence of different types of cancer in children varies across countries. For children aged 0–4 years, leukemia is the most common form of cancer (36.10%), while for adolescents aged 15–19 years, the most common is lymphoma (22.50%) (Steliarova-Foucher et al., 2017). This difference could be due to the level of parental awareness of symptoms experienced by children, the different levels of diagnostic progress in different countries, and how easy it is to access healthcare in different countries. Cancer tends to be undiagnosed in low income countries because there is a lack of awareness or because diagnostic equipment is not available. Social factors also affect the awareness of the population. This population group which more concerned with socioeconomic needs rather than health needs is a challenge for health workers (International Agency for Research on Cancer, 2017).

Sex of Pediatric Cancer Patients

The results of this study indicate that the majority of pediatric patients suffering from cancer are male, with a ratio of 2:1. These results are in line with studies conducted in other countries, for example, research in the USA shows that pediatric cancer incidence and mortality is lower in females compared to males, while survival rates are similar for both sexes (American Cancer Society, 2014). The results of research in the State of Iran also

showed that the prevalence of cancer incidence was higher in boys (Habib et al., 2016). The incidence of cancer in boys in India is higher than in girls. The pediatric cancer incidence is at 235.30 per one million population in boys and in girls as much as 152.30 per one million population in Delhi (Bashar & Thakur, 2018). Similar results have been found in Southeast Asia, with male children in Thailand in 1985–2009 1.4 times more likely to have cancer compared to female children (Wiangnon, Jetsrisuparb, Komvilaisak, & Suwanrungruang, 2014).

In contrast, the prevalence of pediatric cancer in Korea, Japan, and New Zealand is similar for males and females (Katanoda et al., 2017; National Child Cancer Network, 2010; Park et al., 2016), while in East Africa (Ethiopia), it is female children who are more likely to have cancer (Stefan, Bray, Ferlay, Liu, & Parkin, 2017).

Lymphoma is a type of cancer that is more commonly found in male children. The incidence of lymphoma throughout the world is widely reported in the Mediterranean region. Hodgkin's lymphoma is rare type in populations in east and south Asia rather than in other parts of the world. Improvement of socioeconomic conditions can change the incidence of lymphomas in Asia which is also the same with western populations (Steliarova-Foucher et al., 2017).

Genetic factors are also one of the causes of cancer in children. Some cancers in children are closely related to genetic factors, that are fanconi anemia and xeroderma pigmentosum which has a recessive inheritance pattern, as well as retinoblastoma, Li-Fraumeni syndrome, DICER1 syndrome and neurofibromatosis which have a dominant inheritance pattern (Saletta, Pozza, & Byrne, 2015). Data from the CCRP in 1967–2011 showed that the incidence of retinoblastoma was 3.40 per million per year and the incidence of leukemia was 50 per million per year (Isaevska et al., 2017).

Type of Cancer in Pediatric Cancer Patients

The most common form of pediatric cancer is leukemia, followed by lymphoma, brain tumor, neuroblastoma, and bone and soft tissue tumors. Different distributions occur in Africa, however, where Kaposi sarcoma has been found to be the most common type of pediatric cancer in South and East African countries, retinoblastoma the most common in Central African countries, and non-Hodgkin's lymphoma the most common in West African countries (Stefan, Bray, Ferlay, Liu, & Parkin, 2017).

The worldwide incidence of leukemia has increased by 3% each year between 1992 and 2013, largely due to an increase in Acute Lymphoblastic Leukemia (ALL) in White Hispanic children (Barrington-Trimis et al., 2017). The cause of this increase is unknown, but environmental factors are the main suspect (American Cancer Society, 2014). The CCRP reported an increased incidence of cancer, specifically leukemia, central nervous system tumors, and neuroblastoma between 1967 and 2001 (Isaevska et al., 2017), and the incidence of leukemia is also high in South and Southeast Asia (Steliarova-Foucher et al., 2017). This type of cancer has also been dominant in CCRP studies, specifically acute lymphoblastic leukemia (Isaevska et al., 2017).

Research in India and Pakistan has reported that leukemia is more common in male children aged 0–4 years. Indeed, leukemia is the most common childhood cancer globally, accounting for 30–50% of pediatric cancer cases in Eastern Mediterranean countries, 20–40% in the USA, and 40–50% in Europe (Asthana, Labani, Mehra, & Bakhshi, 2018; Badar & Mahmood, 2017). The most common types of leukemia that occur in children and adolescents in the USA are ALL and Acute Myeloblastic Leukemia (AML). Chronic leukemia is very rare in children, whereas ALL occurs in 80% of pediatric leukemia cases and 56% of adolescent cases. ALL is more common in industrialized countries than in developing countries.

Clinical evidence shows that several cases of ALL appear in utero, including ALL concordances in monozygotic twins. Risk factors for ALL include trisomy 21 (Down syndrome), genetic syndromes (e.g. Bloom syndrome, Fanconi anemia, and Nijmegen Breakage syndrome), and congenital immunodeficiency diseases. Higher birth weight has also been linked to a higher risk of ALL, and the International Agency for Cancer Research states that parents who smoke during pregnancy and maternal exposure to paint are also risk factors for leukemia in childhood, especially ALL. Other suspected risks include exposure to pesticides and maternal weight. Atopic events (e.g. allergies, asthma, and hay fever) and folic acid supplementation during pregnancy are protective factors that reduce the risk of ALL (Barrington-Trimis et al., 2017). Interestingly, recent studies have also shown that early exposure to infections (such as in daycare) may play a protective factor for ALL (Ward et al., 2014).

Research Limitation

This study has limited access for a longer period and a wider area, and cannot describe the prevalence in Surabaya generally. Future research requires data from all health services associated with pediatric cancer patients in Surabaya to determine the prevalence of cancer in children in Surabaya. Data regarding the number of children in Surabaya overall is also needed to calculate the prevalence of pediatric cancers.

CONCLUSION

Pediatric cancer patients in the Palliative Care Unit at Dr. Soetomo General Hospital tended to be male and aged 6–10 years or 11–15 years. The most common form of cancer was leukemia. This data can be used to determine therapeutic policies and the therapeutic needs of children with cancer.

CONFLICT OF INTEREST

The authors declare that no conflict of interest in this study.

ACKNOWLEDGMENT

The authors thanks the Palliative Care Unit at Dr. Soetomo General Hospital, Surabaya; the Head of the Palliative Care Unit, Dr. Agus Ali Fauzi; and the Chief Director of Dr. Soetomo General Hospital, who gave us permission to conduct this research. We also thank all the medical staff at the Palliative Care Unit who participated in the data collection.

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