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# A Pilot Study in a Recently Established Childhood Cancer Center for Evaluating the Priority of National Pediatric Cancer Registry

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## Abstract

**Background:** Pediatric cancers account for nearly 2% of all cancers worldwide. In 2018, there were approximately 200,000 newly diagnosed cases of childhood cancer.

**Objectives:** The aim of this study was to assess the need for a national pediatric cancer registry based on case incidence.

**Methods:** This pilot study was conducted on 100 children with cancer who were treated in a recently established pediatric hematology oncology department of Golestan Hospital. Demographic and epidemiological data were collected and analyzed using SPSS software version 25.

**Results:** Sixty-four percent of children with cancer were girls, and the average age of the patients was 7.6 ± 0.42 years. The most common types of cancer diagnosed were leukemia, brain tumor, lymphoma, and retinoblastoma respectively. Metastasis was confirmed in 11 cases. The most prevalent clinical manifestations of cancer included fever, weakness, loss of appetite, paleness, and weight loss.

**Conclusions:** The results of this study align with global rates and data. Based on the findings, the authors emphasize the necessity and priority of establishing a pediatric cancer registry in Iran's health ministry. Therefore, all healthcare workers and specialists in pediatric hematology and oncology should make concerted efforts to establish this registry.

*Keywords:* Cancer Registry, Pediatric, Malignancy

## 1. Background

Nearly 2% of worldwide cancers relate to childhood malignancies in which, leukemia and central nervous system tumors are the most common types of them (1). Childhood malignancies are one of the leading causes of death among children in low- and low-middle-income countries. Significant health challenges in these regions include the increasing number of new cases, delays in diagnosis, the need for updated and affordable care, and effective management of these patients. Additionally, controlling the mortality rate remains a major concern.

One of the main reasons for increasing the incidence and prevalence of pediatric cancers is reported cases from different regions (2). In addition, national pediatric cancer registries could be a priority through controlling and reporting the incidence, mortality, and survival rates of childhood malignancies (3). A database of childhood cancer registry can be useful in controlling cancer care, although its effectiveness is still a major challenge and unclear for many physicians (4).

In 2008, there was a brief review of Iranian national cancer registry which was established jointly with the collaboration of the Tehran University of Medical Sciences (TUMS) and the International Agency for Research on Cancer (IARC) (5). At present, one of the obstacles in Iran is the national pediatric cancer registry which is still a hallmark for health workers and physicians in this area. In Iran, reports of pediatric new cases with malignancies are from national hospital-

based studies and mainly focus on a specific group of malignancies.

## 2. Objectives

According to the mentioned challenges, this pilot study was designed in a recent childhood cancer center in Tehran (the capital city of Iran) for reporting the epidemiology of pediatric new cases with confirmed malignancies. The conductors of this pilot study aimed to evaluate the necessity of the Iranian national pediatric cancer registry.

## 3. Methods

### 3.1. Parvaneh Hematology-Oncology Department

Pediatric cancer centers in Iran are scarce, with most relying on medical universities for support. Despite the limited number of facilities, the incidence of new cases continues to rise. This situation has created a significant need for establishing a new department dedicated to pediatric hematology and oncology. As a response, a charity-run department was founded at Golestan Hospital, funded by the Iranian community, and began operations on January 6, 2022. This department is named in memory of Professor Parvaneh Vossough, may she rest in peace, who was a pioneer in the field of pediatric hematology and oncology in Iran.

### 3.2. Patients

This pilot study was conducted on 100 newly admitted pediatric patients at PHOD from 21 Mar 2022 until 21 Mar 2023. All participants were under 18 years old and had confirmed cases of malignancies, starting their treatment during this period. Patients who chose to discontinue their therapy without any reason were excluded from the study.

### 3.3. Data Gathering & Analysis

All of the epidemiologic and demographic data (such as age, gender, BMI, type of cancer, family history of cancer, clinical manifestations, disease stage, and presence of metastasis) were gathered from the patient's medical documents. Data entered in SPSS software version 23 and in order to determine the normality of the data, the Kolmogorov-Smirnov test was used and (according to the normality of the data), the Pearson (Spearman) correlation coefficient test and linear regression were used. Also, a significance level of less than 0.05 was considered.

## 4. Results

Out of 100 enrolled patients, 36 cases were male (male to female ratio: 0.56). The mean age of patients was 7.6 ± 0.42 years old (age range 1 to 17 years old), and the majority of cases were in the range of 5 to 10 years old. The common confirmed malignancy was Acute Leukemia (n = 52), and the second group was related to brain tumors (n = 15). Table 1 shows the number of cases in each category.

All new cases were evaluated for metastasis and relapse at the time of diagnosis and it was found that only 11 cases had lung metastasis. The clinical manifestations observed in the 31 leukemia patients included fever, weakness, loss of appetite, paleness, and weight loss. . In addition, most patients with brain tumors experienced symptoms such as restlessness, headache, vomiting, and movement disorder.

There was a significant relationship between types of malignancies and sex (P-value = 0.02).

## 5. Discussion

Pediatric patients with cancer are a rare group whose incidence rate is increasing annually. In the United States, 15000 new cases of pediatric malignancies are diagnosed each year (6), although this estimation is somehow impossible in Iran. Because of the lack of a national pediatric cancer registry, all of the childhood cancer data are from rare reports of hospital-based studies or childhood cancer centers. For this limitation, the present study was designed to emphasize establishing a national or Iranian pediatric cancer registry.

In this study, the highest frequency was related to leukemia followed by brain tumors then lymphoma and retinoblastoma as the same. The results of various studies also reported the highest frequency of leukemia cancer. For instance, the results of the study by Mohebi et al. showed that the prevalence of ALL in children with leukemia is higher than that of AML so 84% of children with leukemia were diagnosed as ALL (7). Jafroodi and Ghandi also showed that ALL was the most common leukemia among children in Gilan (8). In a study by Chaudhuri et al., the frequency of acute lymphoblastic leukemia was the highest in children under 14 years of

**Table 1.** Distribution of Sex & Age in Enrolled Cases

| Variables | Gender | | M/F Ratio | Age Groups (y) | | | | Mean Age (y) [a] |
|---|---|---|---|---|---|---|---|---|
| | M | F | | < 5 | 5 - 10 | 10 - 15 | > 15 | |
| **Leukemia (n = 52)** | | | | | | | | |
| ALL (n = 44) | 21 | 23 | 0.91 | 14 | 17 | 10 | 3 | 8 ± 1.2 (4 - 14) |
| AML (n = 8) | 2 | 6 | 0.33 | 1 | 5 | 2 | - | 7.7 ± 0.67 (3 - 17) |
| **Brain tumors (n = 15)** | | | | | | | | |
| MB (n = 5) | 2 | 3 | 0.67 | 1 | 4 | - | - | 5.6 ± 0.9 (3 - 8) |
| PNET (n = 4) | 1 | 3 | 0.33 | 1 | 3 | - | - | 6 ± 1.6 (2 - 9) |
| EP (n = 3) | 1 | 2 | 0.5 | 2 | 1 | - | - | 3.7 ± 1.8 (1 - 7) |
| GB (n = 3) | 1 | 2 | 0.5 | | 1 | 2 | - | 10 ± 1.5 (7 - 12) |
| **Lymphoma (n = 8)** | | | | | | | | |
| NHL (n = 4) | 1 | 3 | 0.33 | 1 | 1 | 2 | - | 9.2 ± 4 (4 - 13) |
| HL (n = 4) | 1 | 3 | 0.33 | - | - | 4 | - | 12.7 ± 0.8 (11 - 15) |
| **Retinoblastoma (n = 8)** | 2 | 6 | 0.33 | 8 | - | - | - | 2.7 ± 0.4 (1 - 4) |
| **Bone sarcoma (n = 5)** | | | | | | | | |
| OS (n = 4) | 1 | 3 | 0.33 | - | 1 | 2 | 1 | 1.3 ± 1.8 (9 - 17) |
| ES (n = 1) | 0 | 1 | 0 | - | - | 1 | - | 15 |
| **Kidney diseases (n = 4)** | | | | | | | | |
| RCC (2) | 0 | 2 | 0 | - | 1 | 1 | - | 10.5 ± 1.5 (9 - 12) |
| WT (n = 2) | 0 | 2 | 0 | - | 2 | - | - | 5.5 ± 0.5 (5 - 6) |
| **Langerhans cell histiocytosis (n = 4)** | 2 | 2 | 1 | 1 | 1 | 2 | - | 7.2 ± 2.4 (1 - 11) |
| **Rhabdomyosarcoma (n = 2)** | 1 | 1 | 1 | 1 | 1 | - | - | 5.5 ± 1.5 (4 - 7) |
| **Hepatocellular cell carcinoma (n = 2)** | 0 | 2 | 0 | - | 1 | 1 | - | 9 ± 3 (6 - 12) |

Abbreviations: M, male; F, female; M/F, male to Female; ALL, acute lymphoblastic leukemia; AML, acute myeloblastic leukemia; MB, medulloblastoma; PNET, primitive neuro ectodermal tumor; EP, ependymoma; GB, glioblastoma; NHL, non-hodgkin lymphoma; HL, hodgkin lymphoma; OS, osteogenic sarcoma; ES, ewing sarcoma; RCC, renal cell carcinoma; WT, Wilms' tumor.

[a] Values are expressed as mean ± SE (age range).

age, followed by retinoblastoma (9). The results of two other studies also showed that the most common malignancies are ALL, followed by osteosarcoma (10.3%) and brain tumors (10, 11). In addition to national reports, in Huang et al.'s study, leukemia, brain tumors, and non-Hodgkin's lymphoma were the most common cancers and the main causes of cancer-related deaths among children (12).

Among children's cancers, lymphoma is the third most common cancer, which has two different classes, including Hodgkin's and non-Hodgkin's lymphoma, and has different clinical manifestations and treatment (13). In the present study, the prevalence of Hodgkin's lymphoma was 4%. Lymphoma in general includes 10 - 12% of all malignancies in children, of which 7 - 10% is related to non-Hodgkin's lymphoma and 4 - 7% is related to Hodgkin's lymphoma (14).

Results showed that the average age of children with cancer was 7.6 ± 0.42 years. In a study, the highest rate of childhood cancer was among people aged 0 to 4 years and 15 to 19 years (15) that was in contrast with the present study. In Mohebi et al.'s study, the average age of children with AML was 100 months (8.33 years), which was higher than the average age of children with ALL (about 69 months) and the difference was statistically significant (7). Hemmatyar and Haji-Naghdi also reported that the average age of children with AML was higher than the average age of children with ALL (16). In our study, no significant relationship was found between age and the prevalence of cancer types, so it can be an announcement as children can confer with cancer at any age.

Presented data showed that 64% of children with cancer were girls. The results of Mohebi et al.'s study showed that the frequency of leukemia and lymphoma in boys was higher than in girls (7), which was consistent with other studies (16-19). The higher frequency of cancer according to gender can be due to gender-related aspects (such as sex hormones) and in

this study, there was a significant relationship between gender and the prevalence of cancer types.

In 2018, there was a published paper from Iran that conducted a cohort study on 2232 pediatric cancer cases in a single center during 9 years of evaluation. Results of the data showed that most patients were less than 5 years old and males were more than females. In that study, authors confirmed leukemia and brain tumors were the common malignancies respectively, followed by sarcoma and retinoblastoma (20).

In our study, fever and weakness, loss of appetite, pallor, and weight loss were the most prevalent symptoms among the clinical manifestations of cancers. In the study of Mohebi et al. (7), in the examination of clinical symptoms and initial manifestations of the disease, it was determined that pallor was the most common clinical symptom, and fever was the most common clinical manifestation. In the study by Hemmatyar and Haji-Naghdi pallor was reported as the most common symptom of leukemia in children (16).

### 5.1. Conclusions

Pediatric patients with cancer represent a distinct and growing group, with an increasing incidence rate each year. The results of this study align with rates and data reported worldwide. Based on the findings, the authors emphasize the urgent need for an Iranian pediatric cancer registry within the health ministry. They call upon healthcare workers and specialists in pediatric hematology oncology to collaborate in establishing this important registry.

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## Footnotes

**Authors' Contribution:** Study concept and design: J. S. and A. M., acquisition of data: A. T., analysis and interpretation of data: N. M., drafting of the manuscript: N. M. and J. S., critical revision of the manuscript for important intellectual content: N. M., statistical analysis: N. M., administrative, technical, and material support: J. S., M. T., A. M., and M. A. E., study supervision: A. M.

**Conflict of Interests Statement:** Azim Mehrvar and Narjes Mehrvar have a first-degree family relationship.

**Data Availability:** The dataset presented in the study is available on request from the corresponding author during submission or after publication.

**Ethical Approval:** The ethical committee of AJA University of Medical Sciences, Tehran, Iran with the ethical committee code IR.AJAUMS.REC.1402.196 .

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## References

1. Stiller C. Epidemiology of Pediatric Cancer. In: Losty PD, Quaglia ML, Sarnacki S, Fuchs J, Taguchi T, editors. *Pediatric Surgical Oncology*. Boca Raton, Fla: CRC Press; 2022. p. 3-9. https://doi.org/10.1201/9781351166126-2.
2. Borah R, Kouya F. Epidemiology of pediatric cancer in the Northwest Region of Cameroon. *medRxiv*. 2020;**Preprint**. https://doi.org/10.1101/2020.02.04.20020487.
3. Kutluk M, Yeşilipek A. Pediatric Cancer Registry in Turkey 2009-2018 (TPOG & TPHD). *J Clin Oncol*. 2019;**37**(15_suppl):e21510. https://doi.org/10.1200/JCO.2019.37.15_suppl.e21510.
4. Rice HE, Englum BR, Gulack BC, Adibe OO, Tracy ET, Kreissman SG, et al. Use of patient registries and administrative datasets for the study of pediatric cancer. *Pediatr Blood Cancer*. 2015;**62**(9):1495-500. [PubMed ID: 25807938]. [PubMed Central ID: PMC4515152]. https://doi.org/10.1002/pbc.25506.
5. Etemadi A, Sadjadi A, Semnani S, Nouraie SM, Khademi H, Bahadori M. Cancer registry in Iran: a brief overview. *Arch Iran Med*. 2008;**11**(5):577-80. [PubMed ID: 18759534].
6. Health NIo. *National Childhood Cancer Registry*. Department of Health and Human Services;; 2023. Available from: https://cancercontrol.cancer.gov/research-emphasis/supplement/childhood-cancer-registry.
7. Mohebi B, Esfahani H, Esna-Ashari F. Epidemiologic Study of Leukemia and Lymphoma in Children Younger than 15 Years Old Referring to Besat Hospital of Hamedan from 2010 to 2020: A Descriptive Study. *J Rafsanjan Univ Med Sci*. 2023;**22**(1):53-64. https://doi.org/10.52547/jrums.22.1.53.
8. Jafroodi M, Ghandi Y. [Epidemiologic Evaluation of Pediatric Malignancies in 17 Shahrivar Hospital]. *J Guilan Univ Med Sci*. 2009;**17**(68):14-21. FA.
9. Chaudhuri K, Sinha A, Hati GC, Karmakar R, Banerjee A. Childhood malignancies at BS Medical College: a ten year study. *Indian J Pathol Microbiol*. 2003;**46**(2):194-6. [PubMed ID: 15022907].
10. Moradi A, Semnani S, Roshandel G, Mirbehbehani N, Keshtkar A, Aarabi M, et al. Incidence of childhood cancers in golestan province of iran. *Iran J Pediatr*. 2010;**20**(3):335-42. [PubMed ID: 23056726]. [PubMed Central ID: PMC3446043].
11. Mousavi SM, Pourfeizi A, Dastgiri S. Childhood cancer in Iran. *J Pediatr Hematol Oncol*. 2010;**32**(5):376-82. [PubMed ID: 20588194]. https://doi.org/10.1097/MPH.0b013e3181e003f7.

12. Huang J, Chan SC, Ngai CH, Lok V, Zhang L, Lucero-Prisno DE, et al. Global incidence, mortality and temporal trends of cancer in children: A joinpoint regression analysis. *Cancer Med*. 2023;**12**(2):1903-11. [PubMed ID: 35822443]. [PubMed Central ID: PMC9883415]. https://doi.org/10.1002/cam4.5009.
13. Bispo JAB, Pinheiro PS, Kobetz EK. Epidemiology and Etiology of Leukemia and Lymphoma. *Cold Spring Harb Perspect Med*. 2020;**10**(6). [PubMed ID: 31727680]. [PubMed Central ID: PMC7263093]. https://doi.org/10.1101/cshperspect.a034819.
14. Gualco G, Klumb CE, Barber GN, Weiss LM, Bacchi CE. Pediatric lymphomas in Brazil. *Clinics (Sao Paulo)*. 2010;**65**(12):1267-77. [PubMed ID: 21340214]. [PubMed Central ID: PMC3020336]. https://doi.org/10.1590/s1807-59322010001200008.
15. Siegel DA, Li J, Henley SJ, Wilson RJ, Lunsford NB, Tai E, et al. Geographic Variation in Pediatric Cancer Incidence - United States, 2003-2014. *MMWR Morb Mortal Wkly Rep*. 2018;**67**(25):707-13. [PubMed ID: 29953430]. [PubMed Central ID: PMC6023185]. https://doi.org/10.15585/mmwr.mm6725a2.
16. Hemmatyar M, Haji-Naghdi M. [Comparison of clinical manifestations and age and sex distribution in childhood acute lymphoblastic leukemia and acute myelocytic leukemia]. *Med Sci J Islamic Azad Univ*. 2005;**15**(3):121-4. FA.
17. Hashemi A, Besharati A, Taghipour S, Bahrami A. [Frequency of various malignant diseases in children younger than 10 years old in Yazd]. *SSU_Journals*. 2007;**14**(4):9-14. FA.
18. Linder LA, Hooke MC. Symptoms in Children Receiving Treatment for Cancer-Part II: Pain, Sadness, and Symptom Clusters. *J Pediatr Oncol Nurs*. 2019;**36**(4):262-79. [PubMed ID: 31307323]. [PubMed Central ID: PMC7197222]. https://doi.org/10.1177/1043454219849578.
19. Utuk EO, Ikpeme EE. Childhood cancers in a referral hospital in south-south Nigeria: a review of the spectrum and outcome of treatment. *Pan Afr Med J*. 2015;**22**:325. [PubMed ID: 26977233]. [PubMed Central ID: PMC4769810]. https://doi.org/10.11604/pamj.2015.22.325.6990.
20. Keramatinia A, Mohseny M, Akbari ME, Mosavi-Jarrahi A, Monfared ED, Amanpour F, et al. Determinants of survival of common childhood cancers in Iran. *J Res Med Sci*. 2018;**23**. [PubMed ID: 30595709]. [PubMed Central ID: PMC6282777]. https://doi.org/10.4103/jrms.JRMS_835_17.