Original Article
http://mjiri.iums.ac.ir
Medical Journal of the Islamic Republic of Iran (MJIRI)

Med J Islam Repub Iran. 2023 (12 Apr);37.37. https://doi.org/10.47176/mjiri.37.37

Establishment of Iran Musculoskeletal Tumor Registry: A Study Protocol and Lessons Learned from Implementation and the Pilot Phase

Khodamorad Jamshidi[1], Abolfazl Bagherifard[1], Kazem Zendehdel[2], Ali Sharifi Kia[3], Abbas Sheikhtaheri[3], Nasim Hashemi[4], Shimasadat Nahvizadeh[1], Alireza Mirzaei[1]*

Received: 23 Nov 2022 Published: 12 Apr 2023

Abstract

Background: The number of available musculoskeletal tumor registries is relatively small. We developed a registry system focused on the clinical aspects of musculoskeletal tumors to improve quality of care indexes through the development of updated national protocols. In this study, we describe our protocol, challenges, and the data collected during the implementation of the registry system in a single-specialty orthopedic center in Iran.

Methods: Three main malignant bone tumors, including osteosarcoma, Ewing sarcoma, and chondrosarcoma, were included in the registry. After establishing a steering committee, we defined the minimum data set based on a literature review and suggestions from an expert panel. Accordingly, the data collection forms and the web-based software were developed. The collected information was categorized into 9 classes, including demographics, socioeconomic data, signs and symptoms, past medical history, family history, laboratory tests, tumor characteristics, primary treatment, and follow-up. Data collection was performed both retrospectively and prospectively.

Results: Until September 21, 2022, a total of 71 patients were registered (21 patients prospectively and 50 patients retrospectively) and consisted of 36 (50.7%) cases of osteosarcoma, 13 (18.3%) cases of Ewing sarcoma, and 22 (31%) cases of chondrosarcoma. The implementation of the registry demonstrated promising data regarding the tumor characteristics, delay patterns, and socioeconomic status of the patients.

Conclusion: The main lessons learned were to develop a monitoring system to make sure that the new staff is adequately trained for the registration process as well as avoid the inclusion of time-consuming useless data in the minimum data set.

Keywords: Musculoskeletal tumor, Registry, Osteosarcoma, Ewing Sarcoma, Chondrosarcoma

Conflicts of Interest: *None declared*
Funding: *This project was funded by Iran University of Medical Sciences (code 97-3-16-12818).*

Cite this article as: Jamshidi Kh, Bagherifard A, Zendehdel K, Sharifi Kia A, Sheikhtaheri A, Hashemi N, Nahvizadeh Sh, Mirzaei A. Establishment of Iran Musculoskeletal Tumor Registry: A Study Protocol and Lessons Learned from Implementation and the Pilot Phase. *Med J Islam Repub Iran.* 2023 (12 Apr);37:37. https://doi.org/10.47176/mjiri.37.37

Introduction

Despite the wide variety of bone tumors, they are relatively rare compared with other tumors such as colorectal or breast cancer. Also, the incidence of malignant bone tumors is lower than benign bone tumors, so bone sarcomas account for approximately 0.2% of all malignancies (1). Even though they are rare, their health burden is sig-

Corresponding author: *Dr Alireza Mirzaei, mirzaeialireza26@gmail.com*

1. Bone and Joint Reconstruction Research Center, Department of Orthopedics, School of Medicine, Iran University of Medical Sciences, Tehran, Iran
2. Cancer Research Center, Cancer Institute, Tehran University of Medical Sciences, Tehran, Iran
3. Department of Health Information Management, School of Health Management and Information Sciences, Iran University of Medical Sciences, Tehran, Iran
4. Iranian Social Security Organization, Tehran, Iran

↑What is "already known" in this topic:
Despite the importance of cancer registries in formulating cancer control programs, only small numbers of bone tumor registries are available around the world. Therefore, little is known about the development of bone tumor registries, and centers aiming at establishing such a registry system should start from scratch.

→What this article adds:
In this study, we described our protocol for the development and implementation of a musculoskeletal tumor registry and discussed lessons learned from the pilot implementation of the system, which could be of great value to those who want to develop similar registry systems.

[DOI: 10.47176/mjiri.37.37]

nificant (2-4). However, their scarcity has led to a limited understanding of all aspects of these tumors, including the treatment outcomes (1).

In Iran, a limited number of reports are available regarding the various aspects of bone tumors, mainly sarcomas. In one of these reports in 2003, Sadighi and Raafat reviewed the clinical characteristics of 1470 sarcoma cases to identify predictors of tumor outcome, relapse, and survival. In children, Ewing tumors and rhabdomyosarcomas were the most frequently observed sarcomas, while osteosarcomas, synovial sarcomas, and malignant fibrous histiocytomas were the most common sarcoma subtypes in the adult population. In total, 25% of patients presented with initial metastasis. They concluded that Iranian patients generally present with large tumors and advanced stage of disease, which results in short survival (5). These data, although old, urge the need for developing national guidelines for earlier diagnosis and better management of sarcoma patients, thereby improving the patient's survival and quality of life.

After the development and implementation of health care quality indicators, it is now well-acknowledged that the evaluation and improvement of health care performance should be based on clinical research and evidence of efficacy, which is linked to an overarching health system (6). Accordingly, cancer-specific quality assessment tools have been developed in several countries, providing performance indicators, including effective health care delivery, patient outcomes, causes of different survival, et cetera (7). However, implementation of these indicators at a population level is generally impractical mainly because of the lack of data source covering these aspects.

Medical registries have shown proven utility in providing valuable epidemiological data regarding various aspects of diseases. To date, the established registries have allowed the development of population-based studies on medical care, early diagnosis, identification of policies that require intervention, et cetera. In several cases, registry data are fundamental parts of disease control programs (8).

Cancer registries are valuable data sources for optimizing clinical care in different health conditions (9). Cancer surveillance through the systematic implementation of evidence-based data obtained from cancer registries plays a vital role in formulating cancer control strategies, thereby improving the success of cancer treatment (9). Despite this importance, only small numbers of cancer registries are available for malignant bone tumors, including the German Interdisciplinary Sarcoma Registry, the Scandinavian Sarcoma Group Registry, Hamburg Bone Tumor Registry, Musculoskeletal Tumor Registry in the United States, and bone and soft tissue tumors Registry in Japan (10).

In Iran, musculoskeletal tumors are registered in the Iranian National Population-based Cancer Registry (PBCR). However, the collected data are limited to the morphology and topology of the tumors, and detailed data on diagnosis, the severity of the disease (ie, stage), treatment, patients outcome, and quality of care of musculoskeletal tumors are not collected in the PBCR of Iran (11-13).

In this study, we aimed to describe our protocol for the development and implementation of a musculoskeletal cancer registry and to discuss lessons learned from the pilot implementation of the system. We also provide a brief report regarding the data obtained from the pilot phase of this registry.

Methods

Registry Purpose and Objectives

Improvement in the quality of clinical care in bone tumors should be supported by the attributed clinical data (7). Since such data source was unavailable in Iran, we have developed a musculoskeletal cancer registry system covering the clinical aspects of bone tumors, including clinical performance, surgical outcomes, patients' survival, et cetera. In this registry, the 3 most common malignant bone tumors, including osteosarcoma, Ewing sarcoma, and chondrosarcoma, were included. The pilot phase of this registry was run in our subspecialized orthopedic hospital, which is one of the leading orthopedic centers in the Middle East, with over 4000 patients yearly referred to its tumor clinic from all over the country and even from neighboring countries. At the same time, we plan to expand it to other hospitals with musculoskeletal tumor divisions at the national level, thereby identifying the difference between clinical care and its impact on tumor outcomes. Our registry also has research objectives adjunct to the clinical objectives, as health care performance improvement should be based on clinical research.

The Clinical Objective of the Registry Includes evaluating the Followings:

- The quality-of-care indexes in bone tumors, including the care delivery, delay map, effectiveness of the treatments, et cetera;
- The outcomes of the same treatment used in different hospitals;
- The outcomes of different treatments used by the same surgeon;
- Using these data to develop national protocols to improve the quality of clinical care in bone tumors.

Research Objectives

- Identifying the natural history of musculoskeletal tumors;
- Providing prognostic disease models based on patient data;
- Improving diagnostic and therapeutic methods in patients with musculoskeletal tumors.

Protocol of the Registry Implementation

Registry Governance Structure

In the first step, we identified all sources of data in the hospital that were required to run this registry, which included the department of medical records and hospital information system, as well as the laboratory, pathology, and radiology departments. Then, we included one representative from each data source center (4 members), mainly the head of the departments, as a member of the steer-

[DOI: 10.47176/mjiri.37.37]

ing committee. In the next step, we contacted all the musculoskeletal tumor surgeons of the hospital and included them in the steering committee (2 members) after the description of the project. The oncologist of the center, who was responsible for adjuvant and neoadjuvant treatment of the patients, was also invited. In addition, 2 experts in health information technology joined the steering committee and helped the team with the standardization and optimization of the registry data management protocol. Finally, the head and deputy chief of the hospital were also included in the steering committee to support the registry and implemented it in the hospital routine. In total, the steering committee included 11 experts. The steering committee was then divided into 3 subcommittees, including the information management committee, data quality assessment committee, and executive committee. The information management committee was responsible for the development of data sets, data dictionaries, data collection forms, and registry software. The quality assessment committee was responsible for evaluating the data quality and providing feedback on the data collection process. The executive committee was responsible for making arrangements with different departments to allow data collection.

Registry Design and Population

This observational study collects the patients' data retrospectively and prospectively. Prospective collection of the data was started on June 22, 2021. In the prospective registry, the new patients with the diagnosis of osteosarcoma, Ewing sarcoma, and chondrosarcoma who were planned to be treated at our hospital are referred to the person in charge of registration. However, in the respective part, we recruited patients who had been treated at our hospital before the start of the program. For this purpose, the list of eligible patients was obtained from the department of medical records and hospital information system. In case of missing preliminary data , we called the patients or their relatives and collected the required data.

The registry inclusion criteria:

- Patients with a histologically confirmed diagnosis of osteosarcoma, chondrosarcoma, or Ewing sarcoma;
- Surgical treatment at the elected hospital.

The registry exclusion criteria:

- Patients whose part of their surgical treatment was performed in another center;
- Patients with significant missing data (Figure 1).

Dataset and Data Collection Forms

To design the initial dataset, we first reviewed the available musculoskeletal tumor registry systems (Table 1). Our survey revealed that most of the available musculoskeletal tumor registry systems, except the Hamburg Bone Tumor Registry, aimed at collecting clinical data besides epidemiologic data. We aimed to include almost all the clinical data collected in the available registries. We also collected some time points in the patients' demographic section, including the date of the first symptom noticed, the date of the first visit by the doctor, the date of the visit by the specialist, et cetera. We aimed to use this information to provide a treatment delay map, thereby developing national guidelines to reduce the delays in treatment as much as possible (14). We also included 2 new sections in our registry, including the socioeconomic status (SES) and laboratory tests that were not included in earlier registries. SES data are acknowledged to significantly impact seeking medical help (15). Therefore, the SES variables were included in this registry to find how they impact the outcome of treatment and the development of strategies to reduce their effect, such as the involvement of charities. *Preoperative labroatory* test results were mainly included for research purposes, such as investigation of their role in

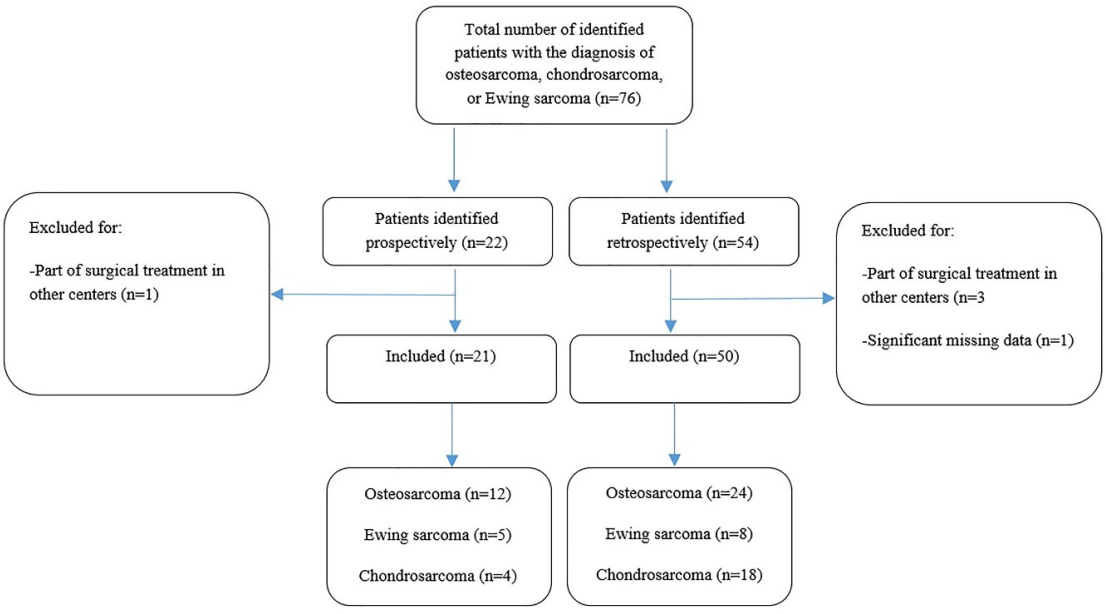

Figure 1. Fellow diagram of the registry

[DOI: 10.47176/mjiri.37.37]

Table 1. Collected data type in available musculoskeletal tumor registries

Registry name	Collected data
Bone and Soft Tissue Tumor Registry in Japan	1) Basic data related to the patient's hospital, sex, age, date of diagnosis, status at the first visit, etc. 2) Information on the tumor: the origin of the tumor (bone, soft tissue), histologic details (malignant or benign, and diagnosis), tumor location, and the data required for TNM and Enneking staging. 3) Information on surgery: date of definitive surgery, type of surgery, reconstruction details, additional surgery for complications, etc.; 4) Information on treatments other than surgery: details of chemotherapy and radiotherapy. 5) Information on prognosis at 2, 5, and 10 years after the initial registration. It includes information on several outcome measures at the time of the latest follow-up, such as local recurrence, distant metastasis, oncologic outcome, and limb salvage status.
German Interdisciplinary Sarcoma Registry	Demographic data, Medical history, Disease history, Eastern Cooperative Oncology Group (ECOG) Performance, Prior, current, and subsequent therapies, Concomitant diseases, Concomitant medication, Histological tests, Survival status, Safety/Adverse Events (AEs), Patient-reported outcomes (PRO; if applicable), Site-specific information.
Scandinavian Sarcoma Group	Data on referral, tumor characteristics, treatment, and outcome with a minimum follow-up of 5 years
The American Academy of Orthopaedic Surgeons (AAOS) Musculoskeletal Tumor Registry	Baseline demographic characteristics of the patients, tumor characteristics, adjuvant treatment, procedural details, implants, adverse events, and outcome measures
Hamburg Bone Tumor Registry	Age, sex, radiological investigations, tumor location, histopathological features including type and dignity of the tumor, and diagnosis.

Table 2. The items of the data set designed for the Iranian musculoskeletal registry system

Section	Items
Demographic data	Patient's identification code, Medical record number, Nationality, National code, First name, Last name, Gender, Age, Place of birth, Ethnicity, Address, Mobile phone number, Due surgeon, BMI, Hospitalization period, date of the first symptom noticed, Date of the first visit by the doctor, Date of the visit by the specialist, Date of diagnosis, Date of admission, Date of treatment.
Socioeconomic items	Family education level, Patient education level (for patients >18 Years), Economic classification of the family, The Smoking status of the patients, The smoking status of the family members
Patient signs and symptoms	Pain duration, Progressively worsening pain, Night pain, Functional pain, Main site of pain, Other symptoms, Duration of symptoms prior to seeking medical attention, Mass, Lymphadenopathy, Loss of function, Fracture at diagnosis, Incidental detection, and surgeon's diagnosis.
Past medical history	Li-Fraumeni syndrome, Previous radiation therapy, Previous Chemotherapy, History of benign bone tumor Paget's disease, Cancers
Family history	Retinoblastoma , Leukemia Musculoskeletal tumor, Bladder Cancer, Breast Cancer, Colon, and Rectal Cancer , *Endometrial Cancer, Kidney Cancer, Liver Cancer, Lung Cancer, M*elanoma, Non-Hodgkin, Pancreatic Cancer, Prostate Cancer, Thyroid Cancer
Laboratory tests	Alkaline phosphatase, Lactate dehydrogenase, WBC, Platelet, Hemoglobin, Hematocrit, ESR, CRP, Calcium, Phosphate
Tumor characteristics	Topography, Laterality, Date of pathologic confirmation, Biopsy type, Pathologic diagnosis, Tumor grade, Tumor size, metastasis at diagnosis, Lymph nodes invasion, Enneking (MSTS) staging, Morphology (diagnosis), Pathologist name
Primary treatment	Type of the primary treatment, Intent of treatment, Date of treatment, Targeted therapy, Chemotherapy, Radiotherapy
Follow-up	Follow-up method, Survival Period, Hospital stay, Date of discharge, Postoperative Complications, Local, Recurrence, Metastasis, Secondary treatment, Follow-up laboratory tests, Limb function (MSTS Score)

*Bold items: items not included in the earlier registries

tumor diagnosis, prognosis, and relapse. While both bone and soft-tissue sarcomas were included in most of the available musculoskeletal tumor registries, we only included bone sarcomas in the present registry.

After reviewing the available registries' data collections, the initial data set was designed in several consecutive sessions with the presence of relevant experts. It included 9 sections, including the patients' demographics, socioeconomic items, signs and symptoms, past medical history, laboratory tests, family history, tumor characteristics, primary treatment, and follow-up. This framework was mainly preserved during the process of registry development. However, many details evolved during the pilot phase. For example, we first included all the comorbidities available in the Charlson comorbidities index (16). We later revised this section only to cover the comorbidities associated with bone tumors, such as Paget disease and Li-Fraumeni syndrome (17). The final data set is summarized in Table 2.

Registry Software

Using the final data set, a web-based registry software was designed by a private software company in Tehran, Iran. The software was developed based on the District Health Information Software 2 (DHIS2) framework using a combination of Persian and English. We used DHIS2 Tracker, which provides a customizable environment for individual-level data entering, tracking, analyzing, and reporting within the DHIS2 platform. Java programing language and PostgreSQL database system were used for this purpose. The system also has a mobile application and is available at http://orthocanreg.ir/

Data Collection Methods

In this registry, patients were recruited both prospectively and retrospectively. For prospective registration, pa-

[DOI: 10.47176/mjiri.37.37]

tients with a confirmed diagnosis of osteosarcoma, Ewing sarcoma, and chondrosarcoma, who were presented to the musculoskeletal tumor clinic of our subspecialized orthopedic hospital and elected for surgical treatment, were referred to the registry department. Trained registrars interviewed the patient or their relatives and collected primary information, including demographic characteristics, socioeconomic data items, past medical history, family history, signs and symptoms, and tumor characteristics.

For retrospective registration, the first name, last name, and medical identification number of the patients with the diagnosis of osteosarcoma, Ewing sarcoma, and chondrosarcoma are obtained from the pathology department. Then, the patient's medical records were reviewed, and patients who had undergone surgical treatment in our hospital were registered. We called the patients or their families to collect the missing information in the medical records. Items including the family history, past medical history, SES, and delay pattern were not collected for retrospective registrations because they were not recorded in the patient's profile.

Data Quality and Quality Assurance

Quality control was performed in 3 categories, including comparability, completeness, and validity. For the comparability of the collected data, we used the International Classification of Diseases for Oncology for coding the topography, morphology, behavior, and grade of the tumors. For the completeness of the registry, all the involved personnel, including the registrars and doctors responsible for referring patients, were adequately trained to not miss eligible patients. We also matched the list of patients referred from the clinic with the list of patients provided by the pathology department to ensure no eligible patient was missed. We made every effort to create a system that can identify errors and prevent the submission of inaccurate data in order to ensure the validity of the data register. To this aim, the patient's national ID is used as the unique identifier in the registry software, thereby preventing duplicate entries. Essential data such as the patients' first names and family names are mandatory, thereby preventing data flaws in essential sections. Also, the software has several data validation rules and checks, such as the normal range and data consistency checks. Therefore, the system will demonstrate an error in case of entering incorrect data. In addition, the obtained data are continuously monitored for unusual trends and frequency of registered cases by a person who is not involved in the registration of patients. The sources of frequent errors are detected, and regular feedback is sent to the person in charge. Regarding the missing data, we contacted the patients' or their relatives and collected the data that were missed at the initial inspection. Also, the re-abstraction method was used to improve the validity of data collection further (18).

Patients Follow-up

The patients' follow-ups are routinely performed every 3 months for the first year, every 6 months for the second year, and yearly afterward. The follow-up aims to record the surgical complications, recurrences, metastasis, death, and survival. The primary treatment and follow-up records are collected by checking the patient's medical records at 6-month intervals. The functional outcomes will also be evaluated using the Musculoskeletal Tumor Society (MSTS) scoring system, which only will be collected for prospectively registered patients (19). In this respect, the registrar calculates the date of MSTS scoring (two years from the surgery date) and puts the adequate MSTS form (upper or lower extremity) in the patient's profile with the due time of evaluation on it.

The software spontaneously calculates survival by subtracting the date of surgery from the date of the last follow-up. If a patient does not attend the planned follow-up visit, the patient's status is inspected through a phone call with the phone numbers recorded in the patient's profile. In case of a referral to another musculoskeletal center or death, this information will be updated in the registry software.

Data Analysis Plan

The data for retrospective and prospective registrations will be analyzed separately. In this respect, a descriptive and inferential analysis will be done when the number of patients in each setting reaches 100. The results of the analysis will be published in the appropriate orthopedic journals. Also, they will be presented to the managers and policymakers through regular annual reports to be used to improve quality care indexes and develop updated national guidelines in bone sarcomas.

Ethical Approval

The research ethics committee approved this study at Iran University of Medical Sciences IR.IUMS.REC.1401.577. Patients provided written informed consent before inclusion in the musculoskeletal tumor registry program.

Results

Between June 22, 2021, and September 21, 2022, we registered 21 patients by the prospective method and 50 patients by the retrospective method, including 36 (50.7%) cases of osteosarcoma, 13 (18.3%) cases of Ewing sarcoma, and 22 (31%) cases of chondrosarcoma. The registered data are summarized in Tables 3-6. We summarized the characteristic features of these patients in this section to show how our registry system works (Tables 3 and 4). The items that were only collected prospectively are summarized in Tables 5 and 6.

Discussion and Lessons Learned from the Implimentation

In the pilot phase of this registry, 71 patients were registered, from whom 21 were registered prospectively and 50 were registered retrospectively. Osteosarcoma was the most commonly registered bone sarcoma during the pilot phase (52.8%). The collected socioeconomic data revealed that most patients were referred from low-income families with a low level of education. Since the pilot phase was performed in a public referral orthopedic hospital, these

[DOI: 10.47176/mjiri.37.37]

Table 3. Demographic and tumor characteristics of registered patients

Variable	Osteosarcoma (n=36)	Ewing sarcoma (n=13)	Chondrosarcoma (n=22)	Missing (n & %)
Age (year)	21.7±10.6 (8-46)	19.4±11 (5-43)	44.8±15 (5-75)	0
Sex				
Male	22 (61.1)	10 (76.9)	9 (40.9)	0
Female	14 (38.9)	3 (23.1)	13 (59.1)	
BMI (kg/m^2)	22.6±5 (13.2-31.9)	18.9±5.1 (14-27.3)	29.5±3.7 (24.3-32.5)	0
Province of residence				
Tehran	8 (22.2)	3 (23.1)	11 (50)	0
Other	28 (77.8)	10 (76.9)	11 (50)	
Site of involvement				
Upper extremity	8 (22.2)	4 (30.8)	0	0
Lower extremity	28 (77.8)	9 (69.2)	4 (100)	
Symptoms				
Pain	34 (94.4)	11 (84.6)	19 (86.3)	
Mass	30 (83.3)	12 (92.3)	18 (81.1)	0
Loss of function	15 (41.7)	8 (61.5)	11 (50)	
None	0	0	0	
Largest tumor dimension (cm)	10±8.1(1-31)	7.9±5.4 (1-157)	8.5±5.1 (1-20)	0
MSTS staging				
IA	3 (8.3)	0	3 (13.6)	0
IB	4 (11.1)	1 (7.7)	2 (9.1)	
IIA	3 (8.3)	1 (7.7)	6 (27.3)	
IIB	24 (66.7)	10 (76.9)	10 (45.5)	
III	2 (5.5)	1 (7.7)	1 (4.5)	
Necrosis (%)	73±20.5 (30-100	79.8±36.4 (15-100)	-	2 (2.8)
Treatment				
• WR	5(13.9)	4 (30.8)	7 (31.8)	0
• WR & R	24 (66.7)	5 (38.4)	7 (31.8)	
• Amputation	7 (19.4)	1 (7.7)	4 (18.2)	
• Curettage	0	3 (23.1)	4 (18.2)	
Hospitalization period (day)	5.7±2.2 (3-12)	5.3±3 (2-14)	5.3±2.5 (2-12)	0

Musculoskeletal Tumor Society; WR: wide resection; R: Reconstruction

Table 4. Preoperative laboratory characteristics of registered patients

Variable	Osteosarcoma (n=36)	Ewing sarcoma (n=13)	Chondrosarcoma (n=22)	Missing number (%)
WBC (10^9/L)	8.1±3.1	7.1±2.7	7.1±1.2	2 (2.8)
Platelet (1000/m^3)	279.8±115	293±157	262±77	2 (2.8)
Hemoglobin (g/dl)	12.3±2.5	12.2±2.3	13.6±2.3	2 (2.8)
Hematocrit (%)	36.3±7.1	35.7±6.2	40.1±6.9	2 (2.8)
ESR (mm/hr)	37.4±31.5	28.1±26.3	17.9±16	2 (2.8)
CRP (mg/L)	21.4±32	26.1±37	8.5±11.1	2 (2.8)
Alkaline phosphatase (U/ml)	565.8±911.5	429.6±304.1	246.6±169	2 (2.8)
Lactate dehydrogenase (U/ml)	526.8±562.7	553±414	329.8±74	2 (2.8)
Calcium (mg/dl)	8.7±2	8.6±2.1	9.1±2	2 (2.8)
Phosphor (mg/dl)	4.2±0.8	4.5±0.8	3.9±0.2	2 (2.8)

Table 5. Delay pattern of prospectively registered patients

Variable	n=21	Missing number (%)
Symptom to first doctor visit (month)	0.81±0.65 (0-2)	2 (9.5)
First visit to specialist visit (month)	1.5±1.4 (0-4)	2 (9.5)
Specialist visit to diagnosis (month)	1.3±1.2 (1-2)	1 (4.7)
Symptom to diagnosis (month)	3.6±1.8 (1-6)	2 (9.5)

observations could be expected. While almost 25% of the patients in the earlier report were referred with metastasis (5), only 4 (5.6%) patients registered in our system had metastasis at the time of referral. This difference could show sooner detection of bone tumors in recent years, which was also consistent with patients' delay map.

Although some bone tumor registries are available worldwide, to the best of our knowledge, this is the first report of a musculoskeletal tumor registry launched in Low and Low Middle-Income Countries (LMIC) such as Iran, with its challenges and specifications. During the pilot implementation of the musculoskeletal registry system, we faced several obstacles to overcome. As our hospital is an educational orthopedic center, the staff involved in the patient's care, including the residents and fellowship-trained specialists, were constantly changing, and we had no choice but to describe the registry program for the new staff and train them for appropriate cooperation, particularly in patients' referral. In this respect, we tried to provide some incentives to encourage them for more active involvement, including their participation in the scientific output resulting from the collected data.

The other difficulty was attributed to the minimum mandatory data items. Most of the data items identified as necessary in the initial phase were either not to be accurately analyzable or even not marked as necessary during the pilot study.

The other difficulty was the lack of cooperation between different wards of the hospital. To solve this problem, we involved the head of the hospital in the registry commit-

[DOI: 10.47176/mjiri.37.37]

Table 6. Past medical history and socioeconomic data of prospectively registered patients

Variable	Osteosarcoma (n=12)	Ewing sarcoma (n=5)	Chondrosarcoma (n=6)	Total (n=21)	Missing
Past medical history					
Yes	0	0	0	0	0
No	12 (100)	5 (100)	6 (100)	21 (100)	
Family history of cancer					
Yes	1 (8.3)	1 (20)	1 (25)	3 (16.7)	0
No	11 (91.7)	4 (80)	3 (75)	18 (83.3)	
Cigarette Smoking					
Yes	1 (8.3)	0	0	1 (4.7)	0
No	11 (91.7)	5 (100)	4 (100)	20 (95.3)	
Waterpipe tobacco smoking					
Yes	0	0	0	0	0
No	12 (100)	5 (100)	4 (100)	21 (100)	
Tobacco consumption by household members					
Yes	1 (8.3)	2 (40)	1 (25)	4 (19)	0
No	11 (91.7)	3 (60)	3 (75)	17 (81)	
Highest education level in the household member					
Illiterate	0	0	0	0	0
Literacy for reading/writing	6 (50)	1 (20)	1 (25)	8 (38.1)	
Diploma	3 (25)	1 (20)	2 (50)	6 (28.6)	
Associate degree	1 (8.3)	1 (20)	1 (25)	3 (14.3)	
Bachelor's degree	1 (8.3)	2 (40)	0	3 (14.3)	0
Master Degree	1 (8.3)	0	0	1 (4.7)	
Doctorate or higher	0	0	0	0	
Economic ladder (1-10)	3.5±2.2 (2-5)	3.8±1.9 (3-5)	3.3±2.2 (2-5)	3.53±2	0

tee, thereby reducing the resistance of medical staff and departments. As earlier studies show, the support of hospital leaders plays a crucial role in the success of the registry programs (20).

Conclusion

Pilot implementation of our bone tumor registry revealed promising data collection regarding the patients' clinical care, tumor characteristics, socioeconomic data, and delay map. Adjunction of follow-up data to this information will further increase its value in improving clinical care indexes in bone tumors—mainly sarcomas. It will be a comprehensive resource for research on bone tumor outcomes. High-quality data for evidence-based policymaking in Iran will be made available through the expansion of this registry to additional sites and the creation of a multicenter or nationwide registry. Given the limited data about surveillance of bone tumors in the LMIC, this registry would show the differences in the presentation and outcome of these patients in these countries compared with the high-income countries, where the most evidence come from.

Acknowledgments

None.

Authors' Contributions

Khodamorad Jamshidi: study design; Abolfazl Bagherifard: study design; Kazem Zendehdel: study design; Ali Sharifi Kia: data collection; Abbas Sheikhtaheri: study design; Nasim Hashemi: study design; Shimasadat Nahvizadeh: data collection; Alireza Mirzaei: study design and drafting manuscript.

Compliance With Ethical Standards

This study was approved by the ethics committee of Iran University of Medical Sciences under the code IR.IUMS.REC.1401.577.

Ethical Declarations

All procedures performed in studies involving human participants were in accordance with the 1964 Helsinki Declaration.

Conflict of Interests

The authors declare that they have no competing interests.

References

1. Franchi A. Epidemiology and classification of bone tumors. Clin Cases Miner Bone Metab. 2012;9(2):92-5.
2. Jamshidi K, Mirzaei A, Bagherifard A, Jahansouz A, Mohaghegh MR. Does the adherence of distal femur parosteal osteosarcoma to the neurovascular bundle increase the rate of local recurrences? Orthop Traumatol Surg Res. 2022;108(4):103220.
3. Jamshidi K, Ramezan Shirazi M, Bagherifard A, Mirzaei A. Curettage, phenolization, and cementation in paediatric Ewing's sarcoma with a complete radiological response to neoadjuvant chemotherapy. Int Orthop. 2019;43(2):467-73.
4. Jamshidi K, Mirzaei A. Long Bone Enchondroma vs. Low-Grade Chondrosarcoma: Current Concepts Review. J Res Orthop Sci. 2017;4(1):0-. eng.
5. Sadighi S, Raafat J. Sarcoma in Iran. Asian Pac J Cancer Prev. 2003;4(2):95-8.
6. Khare SR, Batist G, Bartlett G. Identification of performance indicators across a network of clinical cancer programs. Curr Oncol (Toronto, Ont). 2016;23(2):81-90.
7. Walpole ET, Theile DE, Philpot S, Youl PH. Development and Implementation of a Cancer Quality Index in Queensland, Australia: A Tool for Monitoring Cancer Care. J Oncol Pract. 2019;15(7):e636-e43.
8. Pop B, Fetica B, Blaga ML, Trifa AP, Achimas-Cadariu P, Vlad CI, et al. The role of medical registries, potential applications and limitations. Med Pharm Rep. 2019;92(1):7-14.

[DOI: 10.47176/mjiri.37.37]

9. Parkin DM. The role of cancer registries in cancer control. Int J Clin Oncol. 2008
10. Ebrahimpour A, Tabrizi A, Khabiri SS. Musculoskeletal Tumor Registry, Time to Act and Take Steps Forward. Int J Cancer Manag. 2021;14(11).
11. Ebrahimpour A, Chehrassan M, Sadighi M, Looha MA, Karimi A, Akbari A, et al. The survival and incidence rate of Ewing sarcoma; a national population-based study in Iran (2008-2015). Arch Bone Jt Surg. 2020;8(3):391.
12. Chehrassan M, Ebrahimpour A, Sadighi M, Looha MA, Rad SB, Akbari ME. Epidemiologic trend of mobile spine and sacrum chordoma: A National population-based study. J Craniovertebr Junction Spine. 2020;11(3):226.
13. Ebrahimpour A, Chehrassan M, Sadighi M, Looha MA, Karimi A, Raeisi A, et al. Mobile Spine Osseous Sarcoma: Descriptive Epidemiological Analysis Based on a National Population-Based Study. Arch Iran Med. 2021;24(8).
14. Weller D, Vedsted P, Rubin G, Walter FM, Emery J, Scott S, et al. The Aarhus statement: improving design and reporting of studies on early cancer diagnosis. Br J Cancer. 2012;106(7):1262-7.
15. Clegg LX, Reichman ME, Miller BA, Hankey BF, Singh GK, Lin YD, et al. Impact of socioeconomic status on cancer incidence and stage at diagnosis: selected findings from the surveillance, epidemiology, and end results: National Longitudinal Mortality Study. Cancer Causes Control. 2009;20(4):417-35.
16. Roffman CE, Buchanan J, Allison GT. Charlson Comorbidities Index. J Physiother. 2016;62(3):171.
17. Horvai A, Unni KK. Premalignant conditions of bone. J Orthop Sci. 2006;11(4):412-23.
18. Cook EA, Schneider KM, Robinson J, Wilwert J, Chrischilles E, Pendergast J, et al. Field methods in medical record abstraction: assessing the properties of comparative effectiveness estimates. BMC Health Serv Res. 2014;14:391.
19. Enneking WF, Dunham W, Gebhardt MC, Malawar M, Pritchard DJ. A system for the functional evaluation of reconstructive procedures after surgical treatment of tumors of the musculoskeletal system. Clin Orthop Relat Res. 1993 (286):241-6.
20. Holtrop JS, Hall TL, Rubinson C, Dickinson LM, Glasgow RE. What Makes for Successful Registry Implementation: A Qualitative Comparative Analysis. J Am Board Fam Med. 2017;30(5):657-65.

[DOI: 10.47176/mjiri.37.37]