Proposal for a South African sarcoma registry

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Clinical registries have become a normality in virtually all fields of medicine. Orthopaedics has in many ways led this development with early registries of knee and hip arthroplasties. The South African Orthopaedic Registry (SAOR) is an ambitious undertaking to register *all* orthopaedic procedures performed in South Africa and will provide valuable data for quality assessment, teaching and allocation of resources.[1]

The first collection of data on sarcomas was based on bone pathologists recording histological features and some clinical data. These registries were not population based and had insufficient data on treatment and follow-up. The first sarcoma registry, as we now know them, was the Southern Sweden Sarcoma Registry which was founded by Anders Rydholm in 1970.[2] This registry was expanded into the Scandinavian Sarcoma Group (SSG) Registry by Rydholm and Bauer in 1986 and now encompasses more than 10 000 patients.[3] The type of data collected pertains to referral, diagnostics, tumour characteristics, treatment and follow-up.

Important variables include:

- Whether the patient had been operated on before referral to a sarcoma centre
- Type of biopsy they received
- Tumour size
- Tumour type and grade
- Amputation or limb-sparing surgery
- Surgical margins
- Neoadjuvant ± adjuvant chemotherapy or radiation therapy

During follow-up, development of local recurrence or metastases are recorded. Lastly, cause of death is recorded as tumour-related or not.

Sarcoma registries are the backbone of clinical research. For example, the SSG Registry has been the basis for quality-of-care assessment and for in-depth studies of particular entities and treatment of sarcomas.

Creating standardised sarcoma care pathways may increase clinician awareness and improve referral to sarcoma centres.[4] Goals for specific events such as: time between referral and first visit, time to diagnosis, time to start of treatment, etc., are established. These time goals for the diagnosis and treatment of patients with a sarcoma can be used to assess quality and availability of care at individual institutions and nationally.

Sarcoma care in South Africa is an underdeveloped entity characterised by late presentation of patients, frequent absenteeism, delays in treatment and difficulty in providing treatment due to resource constraints and cultural beliefs.[5] However, the development of the South African Oncology and Limb Salvage Society, along with efforts in the major centres, is helping to improve access to sarcoma treatment for South Africans. Coupled with this are unique practices that include the initial visits to traditional healers together with the more well-known assumption that the musculoskeletal complaints are due to sprains and muscle tears, with physiotherapists and biokineticists being consulted first. Sarcoma-related conditions are also less well known than those of carcinomas such as of the breast and prostate; therefore, soft tissue sarcomas are often considered benign until they are advanced, and the diagnosis reconsidered. Treatment of sarcomas, as described above, is intensive and resource draining both for the service provider and patient.

We currently do not have accurate data on the incidence and prevalence of sarcomas in South Africa and a registry has been a long-term goal of many doctors here. Data is powerful and would

Table I: Proposed variables for sarcoma registry

Characteristics	Treatment	Follow-up
Referral date	Number of surgeries for primary tumour	Date of follow-up
Referral pattern	Date of surgery	Local recurrence
Diagnosis date	Surgery at sarcoma centre	Treatment of recurrence
Age at diagnosis	Local surgery or amputation	Metastases
Metastases at diagnosis	Surgical margin	Treatment of metastases
Preoperative biopsy	Type of reconstruction	Cause of death
Morphological diagnosis	Complications	Date of death
Malignancy grade	Adjuvant treatment	
Tumour site	Date: start of chemotherapy	
Tumour location	Date: start of radiotherapy	
Pathological fracture	Radiotherapy dose and fraction	
Size of primary tumour		

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be useful to motivate for increased education and awareness surrounding sarcomas in South Africa as well as allocation of resources for personnel and treatment. It would also be valuable in guiding research in this field to better understand a South African perspective on the disease and its outcomes.

In order to address these issues, we propose the following plan:

1. Set up a template for a sarcoma registry based upon variables from the SSG Registry but adapt them to fit the local care system in South Africa. A sarcoma registry has been approved by the UCT Faculty of Health Sciences Human Research Ethics Committee R005/2021
2. Start entering patients treated in the Cape Town hospitals, both private and academic
3. Explore the possibility of working with the South African Cancer Registry to locate sarcoma patients that have not been referred to a sarcoma centre
4. Instigate cooperation with other sarcoma centres in South Africa to launch a comprehensive South African Sarcoma Registry

A prospective and population-based sarcoma registry could become an important instrument to monitor quality of care. Reports from the registry would be used to make recommendations regarding referral, diagnostics and treatment. Most data on sarcomas are based on studies from the United States, Japan and Western Europe. A South African registry could be used as a basis for in-depth studies of different sarcoma types in a South African setting.

Maintaining long-term follow-up is always a challenging issue, especially in registries which are not managed or financed as a defined clinical study. In South Africa, follow-up is probably more difficult to achieve because of communication issues between patients and hospitals, lack of electronic patient health records, and problems regarding compliance with follow-up schedules. However, follow-up is not paramount to achieve important information on quality of care. Registering timelines to diagnosis and treatment are valuable measurement tools. Furthermore, tumour and treatment characteristics such as referral patterns, evidence of metastases at diagnosis, surgical margins, rate of limb-sparing surgery, and the proportion of patients receiving adjuvant radiotherapy or chemotherapy, can be compared to data from other population-based registries. They can also be compared to treatment guidelines and followed longitudinally to ascertain whether sarcoma care improves or not. Not least, just comparing the number of patients treated at dedicated sarcoma centres with the expected number based on sarcoma incidence, will tell how many sarcoma patients in South Africa get adequate diagnostics and treatment.

A sarcoma registry will increase knowledge and interest in sarcoma care in South Africa, both at the general and specialist level, thereby improving the quality and accessibility of care. With local data from a South African registry, better decisions can be made around sarcoma treatment. It will also lead to more patients being referred to specialised sarcoma centres, which is paramount for a good oncologic outcome and to afford the least morbid treatment plan to ensure the best functional outcome available. Once a South African registry is set up, a next step could be agreeing on a standardised care pathway for patients suspected of having a sarcoma. Having common goals with respect to referral, time to diagnosis and treatment, and instruments to measure outcome, can be used both for educational purposes and to motivate sufficient resources to enhance quality care of sarcoma patients.

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