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Facilitating Timely Access to Highly Specialized Surgery for Children with Extremity Bone and Soft-Tissue Sarcomas in North and Central India

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Abstract

Background: Optimal management of bone and soft-tissue sarcomas (BSTSs) of the extremity in low- and middle-income countries like India remains a challenge due to the paucity of surgical expertise and other resource limitations. In this study, we aimed to develop a multiple stakeholder model where children with extremity BSTS in North and Central India can access specialized surgery without experiencing cost and delays.

Materials and Methods: The model brought together four stakeholders and developed a pathway of identifying eligible patients, facilitating timely referral, providing specialized surgery, and sharing the cost. Services were offered for 1 year (2018–2019) under this model.

Results: Sixteen non-metastatic patients (69% osteosarcoma, 18% soft-tissue sarcoma, and 13% Ewing sarcoma) from five hospitals received specialized extremity BSTS surgery under this model. About 69% had limb salvage surgeries, 19% rotationplasty, and 12% amputation. Surgery was done at a median interval of 16.9 weeks (range 7.3–33.6 weeks) from the date of diagnosis. None of the patients abandoned treatment. The total cost for the facilitation of the surgery, supportive care and social support for the entire cohort was INR 38.7 lakh (USD 54,180) with an average of INR 2.8 lakh per patient (USD 3920). The patient had to bear no cost toward the surgery.

Conclusions: In this study, we developed a model systematically bringing together four stakeholders and identifying eligible patients, facilitating timely referral, providing specialized surgery at zero cost to the patient, and ensuring completion of treatment and follow-up. Our next goal is to increase the capacity of this model by amplifying its scope and replicating it in other parts of India.

Keywords: Child, Health services accessibility, India, Sarcoma.

Introduction

Sarcomas of the bone and soft-tissue constitute 10% of all cancer in children and young adults [1]. The incidence of Ewing sarcoma and osteosarcoma peaks in the 15–19 years age group with the long bones of lower limb and upper limb constituting the most common location for these tumors [2]. A significant minority of childhood soft-tissue sarcomas also occur in extremities [3]. Multidisciplinary management is the hallmark of these cancers and is characterized by systemic chemotherapy, timely local control involving non-mutilating surgery, and administration of radiation when indicated. This can achieve long-term cure in two out of three children with these cancers [4].

Optimal management of these cancers in low- and middle-income countries (LMICs) like India remains a challenge. There are delays in presentation leading to locally advanced disease making limb salvage surgeries less feasible as well as distant spread, leading to poor cure rates [5]. The challenge is further compounded by the absence of trained orthopedic oncologists specializing in sarcoma surgery. In LMIC, a lot of tumor surgery is still being done by general surgeons and general orthopedic surgeons with limited knowledge of the principles of musculoskeletal oncology(MSK) [6]. Delayed, inadequate, and inappropriate surgery leads to need for additional surgery, increased morbidity, and poorer survival [5, 6, 7]. This further leads to abandonment of treatment and high social and occupational dysfunction.

Cankids, a national not-for-profit organisation working for childhood cancer in India, has previously been facilitating ad hoc surgeries for extremity bone and soft-tissue sarcoma (BSTS) for children across India. In this study, we developed a model systematically bringing together four stakeholders and identifying eligible patients, facilitating timely referral, providing specialized surgery at zero cost to the patient,

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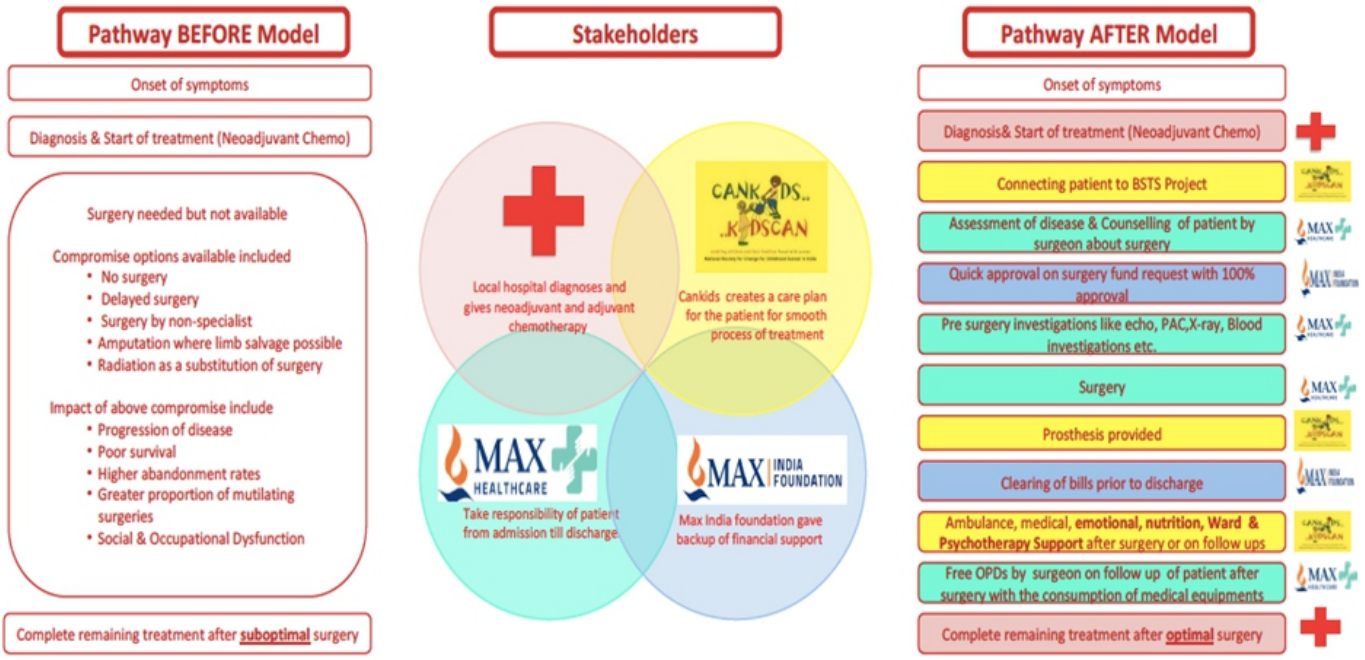

Figure 1: The model for providing specialized timely surgery to children with bone and soft-tissue sarcomas of the extremity.

and ensuring completion of treatment and follow-up. The aim was to develop a model where children with extremity BSTS in India can access surgical expertise without experiencing cost and delays.

Materials and Methods

The development of the model needed three key ingredients:

1. Identifying children with extremity BSTS
2. Identifying hospital and surgeon with expertise to conduct the surgery
3. Raising resources for making this happen.

To identify the children, Cankids used its network of Cankids Hospital Support Units (CHSUs) in North and Central India in partnership with the local hospitals to create awareness of the model which can potentially benefit children with extremity BSTS. Social workers at each of these CHSUs were asked to discuss this with their respective clinicians and flagup eligible patients. In the model, the patient received neoadjuvant and adjuvant chemotherapy at their local hospital and the surgery at Max Super Speciality Hospital, Saket.

Max Super Speciality Hospital, Saket, New Delhi (part of Max Healthcare) and its MSK Disease Management Group (DMG) offered to provide this service. The MSK DMG at Max is well developed and has a full complement of orthopedic oncosurgeon, pediatric/medical oncologist, radiation oncologist, pathologist, and radiologist besides a data entry operator and a social worker.

To raise the resources, three stakeholders stepped forward

- Max India Foundation (corporate social responsibility arm of Max Group including Max Healthcare)– would fund majority of the cost
- Max Healthcare (provider of tertiary and quaternary health services in North India) provided a discount on the total bill
- Cankids provided the following services:
- During surgery –Paid for the prosthesis implant
- Post-surgery –Cankids provided post-operative care including 7–10 days stay, pain and symptoms management, post-operative rehabilitation, psychological support, and nutrition counseling.

The overall model is shown in Fig. 1. It was agreed to offer services to the patient on this model for 1 year (2018–2019) for the children <21 years with extremity BSTS. The study involved streamlining of services to deliver appropriate standard of healthcare and hence institutional ethics approval was not sought.

Results

The following hospitals in North and Central India were identified where eligible patients would be offered the service:

1. Indraprastha Apollo Hospital, New Delhi
2. Kamla Nehru Memorial Hospital, Allahabad
3. King George Medical University, Lucknow
4. Lok Narayan Jai Prakash Hospital, New Delhi
5. Mahavir Cancer Sansthan, Patna
6. Max Super Speciality Hospital, Saket, New Delhi
7. Super Speciality Paediatric Hospital and Post Graduate Teaching Institute, Noida
8. Sher-i-Kashmir Institute of Medical Sciences, Jammu and Kashmir.

At the weekly online meetings, social workers from these CHSUs were informed and explained about the way they are supposed to identify the eligible patients and refer them to Max Super Speciality Hospital, Saket, for timely and appropriate surgery.

Sixteen patients (31% of female, median age 11 years) from five hospitals received specialized extremity BSTS surgery under this model. About 69% of patients had osteosarcoma, 18% soft tissue sarcoma, 13% Ewing sarcoma, and all were non-metastatic. About 69% (11 patients) had limb salvage surgeries (artificial prosthesis five patients, extracorporeal radiotherapy (ECRT) and reimplantation four patients, and wide local excision two patients), 19% had rotationplasty, and 12% had an amputation. Surgery was done at a median interval of 16.9 weeks (range 7.3–33.6 weeks) from the date of diagnosis. At a median follow-up of 17.4 months after diagnosis and median follow-up 12.2 months after surgery, 81% of patients are

alive and disease free. Three patients have died, two with disease while in one the cause is not known. None of the patients abandoned treatment. All four patients with prosthesis and three patients with rotationplasty were walking independently at the time of the last follow-up. All patients with ECRT showed union at the last follow-up and were walking with support. One patient treated by ECRT of tibia had late post-operative infection that required debridement. There were no secondary amputations.

The total cost for the facilitation of the surgery and other supportive and social support for the entire cohort was INR 38.7 lakh (USD 54,180) with an average of INR 2.8 lakh per patient (USD 3920). Out of the whole cost, discount from Max Healthcare contributed 13%, contribution by Max India Foundation was 67% and Cankids shared 20% of the cost burden and provided 12 days of stay per child at the Pediatric Palliative Care Project Centre. The patient had to bear no cost toward the surgery.

Discussion

Outcomes of pediatric sarcomas in LMIC lag behind those from high-income countries [4,8]. Deficits in trained workforce, infrastructure capacity, supportive care, and multidisciplinary teams are key barriers, all of which are underpinned by lack of resources [9, 10]. Similar challenges have been noted in the Indian context as well [5]. Our model aimed to overcome these challenges and facilitated timely access to highly specialized surgery for children with extremity BSTS in North and Central India by bringing together several stakeholders. Our initial experience suggests that this model is feasible with timely surgery and has good short-term outcomes including 12.5% rate of amputation, no abandonment of treatment, and with no extra cost to the family.

Worldwide and in India, there are now an increasing number of efforts to address the health-care system barriers to improve outcomes of childhood cancers. These efforts, both singly and in combination, have demonstrated success and form the template for others to emulate. Some of these include interventions for acute lymphoblastic leukemia and embryonal tumors such as Wilms' tumor [11, 12, 13]. We are not aware of any similar specific initiatives which have been done in the area of childhood BSTS. Our experience adds to the growing list of global initiatives on childhood cancer, which are looking at improving childhood cancer care in LMIC.

Conclusion

The main limitation of this study is that it remains to be seen if this model can be scaled up. Our next goal is to increase the capacity of this model by amplifying its scope and replicating it in other parts of India. This clearly has resource implications and the long-term sustainability of this model needs to be evaluated.

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