Oncology
and Radiotherapy ©
1 (51) 2020: 001-005 • RESEARCH ARTICLE

National childhood cancer comprehensive management policy-a road map

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SUMMARY

Background: In India, the burden of delay in early diagnosis of childhood cancer and treatment is higher than previously suggested. Government policies in collaboration with all sections of society are required to improve care for children with cancer. This proposal outlines an early diagnosis and shared care model integrating palliative care into paediatric oncology with civil society participation in Karnataka, thereby the implementation of a National Policy.

Objectives:

1. To identify the incidence, pattern, region and district-wide distribution of childhood cancers in Karnataka

2. To formulate a draft state childhood cancer comprehensive management policy

3. To Identify a National Health Programme/s formulate a pathway to implement the policy

The Methodology of Preparing this Proposal: Hospital Based Cancer Registry was analyzed, World Health Organization's (WHO) resources were searched, and communication with Government authorities for policy implementation followed by focused group discussion with concerned faculty and representatives.

Results: 3305 childhood malignancies (0-18 years) were registered between the Year 2010-2015. 85.26% hailed from Karnataka. 60.9% were Boys and 42.2% were 7-14 Years.

Focused group discussion resulted in the formulation of the referral pathway, shared care model integrating palliative care services and creation of a platform for civil society organizations' participation.

Conclusion: A comprehensive childhood cancer policy ensuring early diagnosis through a shared care model and integrating palliative care into paediatric oncology practice in the form of well-structured and collective studies conducted are required to evolve a national collaborative policy aiming at reduction in the geographical gaps in treatment facilities. the same model may be incorporated into the management of other Childhood conditions.

Key words: childhood cancer, comprehensive management, health centers, malignancies

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Word count: 2616 **Tables:** 02 **Figures:** 03 **References:** 12

Received: - 18 December, 2019

Accepted: - 24 December, 2019

Published: - 02 January, 2020

INTRODUCTION

There is an increasing proportion of newly diagnosed childhood cancers annually. Early diagnosis improves outcomes, more so in the developing countries where most of them present late or in a sick state to the referral institute [1]. The burden of childhood cancer in India is substantially higher than previously suggested. In a study recently done in New Delhi, Median time to treatment for children with cancer was nearly two months from the onset of symptoms. Median one-way travel distance was 338 km and travel time 9 hours from their usual place of residence to their current location for treatment. The situation in Karnataka is the same. The government of India in its National Policy for Children 2013 affirms the commitment to ensure equitable access to comprehensive health care of the highest standard for all children throughout the period of their growth and development. The National Plan of Action for children 2016, which is an expression of Constitutional and Policy Commitments made for Children of India ensures Palliative care and support services for children with various illnesses including cancer through Ministries of Health and Family Welfare and Women and Child Development, Panchayati Raj Institutions and Non-Governmental Organizations (NGOs). The National Health Policy 2017 envisions quality palliative care services to the children and adolescents through the public health sector at the community level, primary health centers, and district hospitals. Targeted interventions by all stakeholders coupled with policy changes are required to improve the access to care for children with cancer in India [2]. Although Governments have primary responsibility for effectively improving outcomes of childhood malignancies, collaboration and engagement of all sections of society enhance success. World Health Organization urges member states to involve all stakeholders in cancer control planning, implementation, assessment, including NGOs and community-based organizations. There is a need for national strategies aimed at improving outcomes for Indian children with cancer [3]. Hence this proposal outlines an early diagnosis module and shared care model which includes integrating palliative care into paediatric oncology services [4] facilitating civil society participation in the state of Karnataka, and once implemented the learning experiences can lead to a national policy [5].

OBJECTIVES

1. To identify the incidence, pattern and region and district-wide distribution of childhood cancers in Karnataka [6]

2. To formulate a draft state childhood cancer comprehensive management policy for consideration government of Karnataka, which includes shared care model integrating paediatric palliative care services throughout the continuum of care and at all levels of public health delivery system, aiming at reduction in the geographical gaps in healthcare facilities with a platform for civic society participation [7]

3. Identify a National Health Programme/s to implement the above policy

4. To formulate a pathway to implement the above policy

METHODOLOGY OF PREPARING THIS PROPOSAL

1. The Hospital Based Cancer Registry of Kidwai Memorial Institute of Oncology (KMIO), Bengaluru was analyzed to identify the region and district-wide distribution of childhood cancers in Karnataka

2. World Health Organization's (WHO) resources were searched for an early Diagnosis of Childhood Cancer Manual [8]

3. Communication was sent to the Government of India (GoI) as to what is the programme to implement the early diagnosis of childhood cancer module

4. A focused group discussion was held among the faculty and staff of departments of paediatric oncology, pain and palliative medicine, epidemiology and biostatistics, Kidwai Memorial Institute of Oncology, and Representatives of Civil Society Organizations to draw in pathway of a shared care model integrating palliative care services into paediatric oncology

RESULTS

A total number of 3305 childhood malignancies (0-18 Years) (6.1% Total Registrations) were registered at KMIO between the year 2010-2015. Children belonging to the state of Karnataka among them were 2818 (85.26%) [9].

1717 (60.9%) were boys and 1101 (39.1%) were girls. 463 (16.4%) were 0-3 Years, 587 (20.8%) were 4-6 Years, 1189 (42.2%) were 7-14 Years and 579 (20.5%) were 15-18 Years.

1339 (47.5%) were from Bengaluru region (9 districts), 423 (15.0%) were from Belgaum Region (7 districts), 491 (17.4%) were from Gulbarga region (6 districts) and 565 (20.0%) from Mysore region (8 districts).

The overall pattern of childhood cancers (0-14 Years) as per International Childhood Cancer Classification 3rd. edition is as per Table 1.

Infant malignancies constituted 6.24%. Among them, 77.7% were solid tumors and 22.3% were hematological malignancies.

Neonatal malignancies constituted 1.39%. Among them, 83.33% were solid tumors and 16.67 were hematological malignancies (Figure 1).

Tab. 1. Overall pattern of childhood cancers

S. No	Childhood malignancy group	Percentage
1	Leukemia	44.70%
2	CNS neoplasms	13.80%
3	Lymphoma	11.95
4	Other malignant neoplasms	6.90%
5	Malignant bone tumors	5.70%
6	Renal tumors	4.80%
7	Soft tissue sarcomas	4.30%
8	Neuroblastoma	3.10%
9	Germ cell tumors	3.10%
10	Retinoblastoma	1.70%
11	Hepatic tumor	0.20%

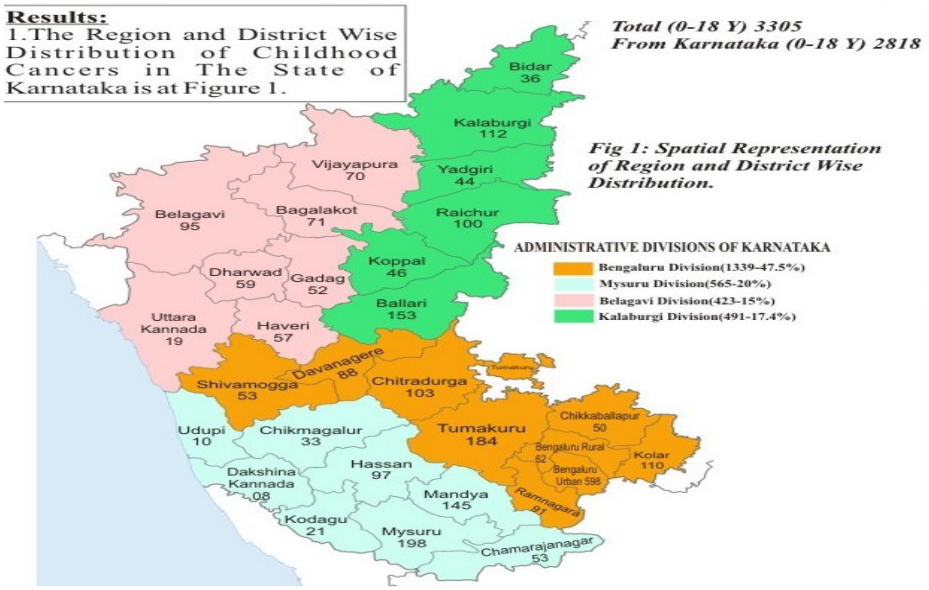

Fig. 1. The region and district wise spatial distribution

Tab. 2. Classification table for cancer probability in children

Assess	Classify	Action
One of the following • Fever for over 7 days with n apparent cause • Headache: Persistent and progressive, and primarily nocturnal, that awakens the child or appears when rising in the morning and maybe accompanied by vomiting • Bone pain that has increased progressively in the last month and disrupts the child's activities • Petechiae, bruises, and/or bleeding • Severe palmar or conjunctival pallor • Leukokoria (White-eye) • Strabismus that has newly appeared • Aniridia (lack of iris) • Heterochromia (different colored eyes) • Hyphema (Blood in the eye) • Proptosis (bulging eye) • Nodes>2.5 cm in diameter, hard, painless, lasting>=4 weeks • Acute and/or progressive focal neurological signs and symptoms: i. Convulsion without fever or underlying neurological disease ii. Unilateral weakness (of one limb or one side of the body) iii. Physical asymmetry (Facial) iv. Changes in consciousness or mental status (Behavior change, confusion) v. Loss of balance when working vi. Limping from pain vii. Difficulty speaking • Visual disturbances (blurred, double, sudden blinding) • Palpable abdominal mass • Hepatomegaly and/or splenomegaly • Mass in some region of the body with no signs of inflammation	POSSIBLE CANCER OR VERY SEVERE DISEASE	• Refer urgently to the nearest medical college hospital's department of pediatrics for stabilization • If necessary begin intravenous fluids, oxygen and pain management • If a brain tumor is suspected and there is neurological deterioration give one dose of injection dexamethasone 4 mg iv Stat • Speak with parents and explain the need and importance of the referral and its urgency • Resolve all administrative problem that occurs • Communicate with the referral facility
One of the following • Loss of appetite in the last 3 months • Weight loss in the last 3 months • Tiredness or fatigue in the last 3 months • Significant night sweets, with no apparent causes • Mild palmar or conjunctival pallor • Painfull lymphadenopathy or lasting <4 weeks or<=2.5 cm in diameter, or not hard in consistency	SOME RISK OF CANCER OR SEVERE DISEASE	• Do a complete physical examination to look for a cause for the signs founded • Revive the child diet and correct any problem found • Refer for RBSK pediatric consultation: i. Treat a possible cause if found ii. Teach danger signs immediately iii. Follow-up in 14 days if there is no improvement and refer as above
Does not meet criteria for be classified in either of the above classifications	Does not have cancer	• Ensure immunization and growth and development monitoring • Ensure Immunization and growth and development monitoring • Ensure a tobacco-free environment • Recommend a healthy diet and regular physical activity

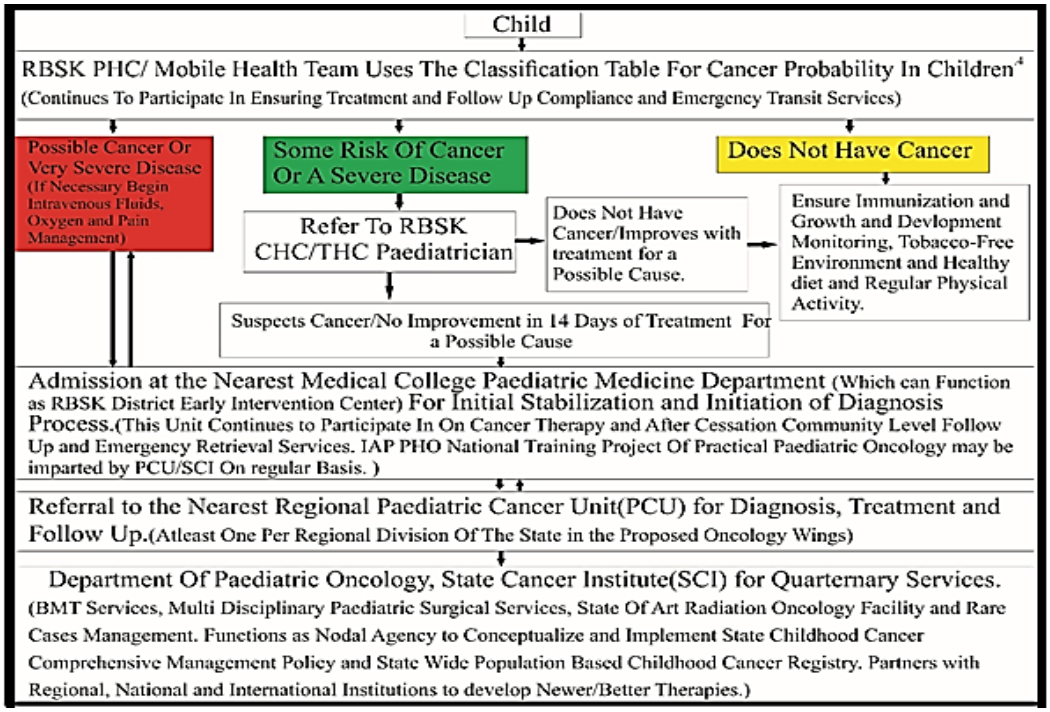

Fig. 2. Shared care module (draft) formulated as a result of the focused group discussion

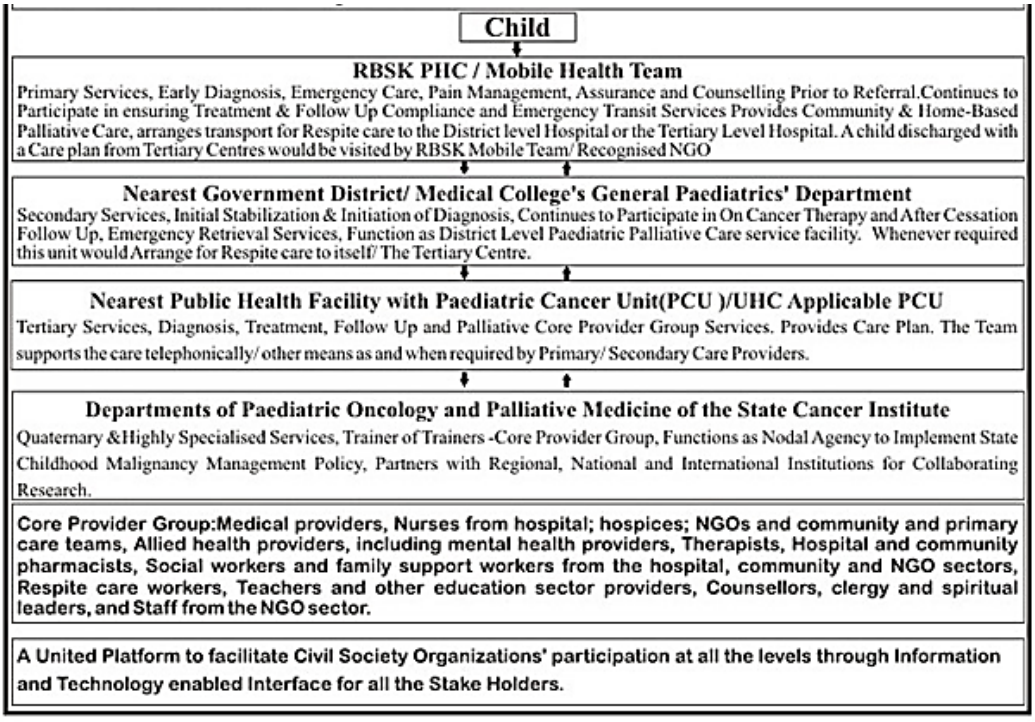

Fig. 3. Integrated pediatric oncology palliative care pathway formulated as a result of the focused group discussion

WHO Publications' search yielded in a manual build on the methodology established by the Pan American Health Organization (PAHO)/WHO regional office for Americas intended for use as part of the compendium of Integrated Management of

Childhood Illness' resources for primary care providers. This document also addresses palliative care issues like pain management, assurance and counselling and arranging support services prior to referral. A classification table for cancer probability was children adapted from this document [10] (Table 2).

Government of India in its letter No F.No.2-28020/12/2017-CH dated 30th/November/2017 clarified Rashtriya Bal Swasthya Karyakram (RBSK) is the Programme through which the module of early diagnosis of childhood cancers can be implemented.

A focused group discussion resulted formulation of referral pathway along with the conglomeration of proposed classification table for cancer probability in children for use by RBSK and

a shared care model integrating palliative care services and the creation of a platform for civil society organizations' participation. shared care module (draft) formulated as a result of the Focused Group Discussion) (Figures 2 and 3).

DISCUSSION

In the circumstances mentioned in the background, it's prudent Government of Karnataka evolves a state childhood cancer comprehensive management policy (Early diagnosis of childhood cancer by community-level RBSK team and optimal shared care pathway {Admission at the nearest secondary facility-government medical college hospital/ district hospital, referral to the tertiary care institute, continued participation in the shared care towards community-level follow up while on cancer therapy and after therapy, emergency retrieval services, integrating paediatric palliative care services throughout the continuum of care and at all levels of public health delivery system and more so when the disease progresses/relapses and all the available curative treatment options have been exhausted} and providing a platform for Civil Society Organizations' participation)

Integrated paediatric oncology palliative care services

Paediatric Palliative care Is the active, total care of the child's body, mind the spirit. It begins at diagnosis and continues whether the child receives treatment or not for the disease. It involves supporting the entire family as well as the child. It requires a multi-disciplinary approach that makes use of community resources. The same can be provided in tertiary care facilities, community health centers and children's homes. It plays an important role when the definitive treatment has failed, and all the available realistic curative options have been exhausted. A WHO publication on integrating palliative care and symptom relief into paediatric services can be used by programme managers for the implementation of the services [11].

The measures required are

Training of RBSK Personnel (Both PHC and Mobile Teams) on early diagnosis of childhood malignancies' module a provision of home-based and community based paediatric palliative care services.

Early diagnosis of childhood cancer initiated at the community level also helps in identifying other severe diseases. provision of paediatric palliative care services addresses other chronic paediatric illnesses also.

Training of RBSK Paediatricians and Government Medical Colleges' Paediatric Medicine Faculty (One/ College) on lines of National Training Project on Practical Paediatric Oncology complied by Indian Academy of Paediatrics' Paediatric Haematology Oncology (PHO) Chapter. Training shall also include the establishment and provision of district Level Paediatric palliative care services. This personnel can later function as trainer of trainers. Real-time data sharing between all the stakeholders pertaining to regional and district wise distribution of childhood malignancies is essential to plan child health care delivery policy. This can be achieved by using state of art Information and technology tools like the internet of things and blockchain. Unified Platform to facilitate the participation of NGOs [12] and other Civil Society Stakeholders working closely for children with cancers and their caregivers to provide holistic care throughout the journey of diagnosis, treatment, surveillance and long-term follow up and palliative care.

CONCLUSION

A comprehensive childhood cancer policy ensuring early diagnosis through a shared care model and integrating palliative care into peadiatric oncology practice is in the best interest of a child and upholds their rights guaranteed by constitution of India (Article 15 (3)), Legislation (Juvenile Justice Act), National Health Policy (2017) and United Nations Convention on the Rights of the child, to which India is a Signatory (Articles 2, 3, 6, 12, 13, 24, 28, 31 and 37).

Well-structured and collective studies conducted by National and State Government Departments and Agencies, Regional Cancer Centers, Medical Colleges and Public Health Academia are required to evolve a National Collaborative Policy aiming at Reduction in the geographical gaps in treatment facilities.

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