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A Situational Analysis of Childhood Cancer Care Services in India 2022

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A Situational Analysis of Childhood Cancer Care Services in India

2022

ICMR – National Centre for Disease Informatics and Research, Bengaluru

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Message

Childhood cancers contribute to a reasonable quantum of morbidity and mortality among children and adolescents. The current childhood health programmes focus on infectious diseases and nutritional problems, while the cancer control programmes aim to prevent and control cancer in adults. Hence, childhood cancers have not received the due attention, resulting in delays in diagnosis and treatment with consequent poor disease outcomes since children with cancer often present with advanced-stage disease. Lack of sturdy referral systems is one of the reasons for late-stage presentations and delayed diagnosis.

The 'Situational Analysis of Childhood Cancer Care Services in India' conducted by the WHO and ICMR-NCDIR, MoHFW aimed to describe the status and challenges in delivering quality childhood cancer services. The survey has attempted to provide a nationwide presentation by including tertiary and secondary level hospitals in 27 states and 3 union territories and concerned state health officials and non-profit organisations engaged with childhood cancer care.

The findings in this report could be used to accelerate the preparedness and capacity of the health system to address childhood cancer in India. Multisectoral efforts to enhance awareness, treatment-seeking and treatment adherence, combined with robust policy implementation, would be of immense help in improving survival in patients of childhood cancer.

(Dr Sudarsan Mandal)

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Message

The landscape of childhood cancer is witnessing a changing trend, and is a cause of major concern. The recent findings from the National Cancer Registry Programme reportshave shown that the proportion of childhood cancers (0-14 years) relative to all cancers was 4%. Data from the Population Based Cancer Registries indicate variations in childhood cancer incidence in different registry covered areas throughout the country. Compared to higher-income countries, the survival rate of childhood cancers is less in India and is mainly attributed to delays in care-seeking, delayed diagnosis and low treatment adherence.

There is absence of a childhood cancer policy and program in the country. To start the process study entitled ' Situational analysis of childhood cancer care services in India' was conducted by ICMR-NCDIR, with support from the World Health Organization, for a comprehensive description of the status of childhood care services available at tertiary and secondary level care hospitals across the country. The study attempted to describe the obstacles in delivering optimal care and factors that could be conducive to strengthening childhood cancer care services in India.

I hope this report will be a valuable resource for stakeholders concerned with childhood cancer care services in the country and encourage appropriate research.This would pave the way for formulating suitable policy and programmatic interventions for addressing childhood cancer care.

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Message

Cancer is a one of the leading causes of death for children and adolescents in India. More than 80% of children with cancer can be treated and cured. However, late diagnosis, inaccessible therapy, lack of skilled workforce, inadequate diagnostics facilities, treatment inertia and avoidable relapse result in lower survival rates.

The cause for a vast majority of childhood cancers is unknown, which makes prevention challenging. Early diagnosis followed by effective, evidence-based therapy and customised supportive care is the most effective strategy to reduce the cancer burden in children and improve outcomes. Paediatric palliative care, while a core component of comprehensive care, is often neglected.

The World Health Organization (WHO) Global Initiative for Childhood Cancer is part of the response to the World Health Assembly resolution on cancer prevention and control through an integrated approach (WHA70.12). The initiative aims to increase political commitment for childhood cancer control; develop standards and tools to guide interventions for early diagnosis, treatment, palliative care, and survivorship care; improve access to essential medicine and technologies; and protect families from financial hardship and social isolation as a result of cancer care.

The South-East Asia Regional Office has set up SEAR Childhood Cancer Network to support member countries to improve knowledge on the latest evidence-based interventions and build capacity for a strong childhood cancer response.

WHO India, in collaboration with ICMR National Centre for Disease Informatics and Research, conducted a situation analysis of childhood cancer services at the national and subnational levels to assess the availability of childhood cancer care services, treatment practices, care pathways and to document facility preparedness for the provision of childhood cancer care services. Key informant interviews with state programme managers, cancer institutions (public and private), and civil society organisations across country have helped in framing barriers and facilitators in childhood cancer service delivery to optimise treatment and care.

We are confident that the findings from the assessment will help narrow critical gaps in information. The high-quality data will inform national policies, strategies and interventions to improve survival and the quality of life of paediatric cancer patients across the country.

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Foreword

Cancers are an increasing burden on individuals and society. The latest ICMR-NCDIR National Cancer Registry Report 2021 showed that childhood cancers (0-14 years) accounted for 4% of all cancers recorded between 2012-2019. These cancers occur at younger ages and have no established known preventive steps to be taken. Thus the mainstay of handling them is efficient treatment and care. In the absence of any policy or program specifically addressing childhood cancers in India, the necessary impetus is lacking. To begin the process, with the support and collaboration of the World Health Organization (WHO India and Regional Offices), a national level survey on comprehensive situational analysis of childhood cancer care services in India was undertaken to describe the landscape of such services and identify gaps, which would help to improve the quality of care and survival outcomes.

The report "A situational analysis of childhood cancer care services in India" describes the rationale, methodology and results of this study that was conducted in 137 tertiary and 101 secondary level hospitals (public, private and not-for profit) in 26 States and 4 Union Territories. Data was captured through software based tools on aspects related to diagnosis, referral, treatment, availability of equipment's/drugs/devices, human resources, teaching and training programs, challenges in managing childhood cancers and policy interventions needed. The concerned hospital key informant, state NPCDCS nodal officers and civil society organizations were also assessed for their views on these topics and suggestions on scaling and strengthening of childhood cancer care services in India.

It is hoped that this report will help in formulating relevant discussions around childhood cancer care services in the country and development of a policy to address its needs.

Prashant Mathur

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Executive summary

Background

Childhood cancer constitutes the invisible portion of the "cancer iceberg" to a large extent. The proportion of childhood cancers in India contributing to the global statistics is significant. In this context, the narrative of childhood cancer care services gains importance. Delayed diagnosis and treatment initiation are the commonly proposed reasons for poor survival outcomes in childhood cancer. Assessing the present situation of childhood cancer care services is essential to suggest reforms and shape programmatic and policy interventions. The survey aimed to assess the status of childhood cancer care services in India regarding availability, facility preparedness and capacity, treatment-related practices, and perceived barriers and facilitators in diagnosing and treating childhood cancers.

Methodology

The ICMR- National Centre for Disease Informatics and Research (NCDIR), the central coordinating agency, provided technical support, including overall supervision, study tools and an online portal, survey implementation, and data management and statistical analysis. The situational analysis was conducted using a cross-sectional survey design. The participants included 137 tertiary level hospitals, 92 secondary level hospitals, 16 state nodal officers for NPCDCS and nine civil society organizations/non-governmental organizations (CSOs/NGOs) in 26 states and four union territories (UT). A nodal hospital was identified in each state/ UT and required to further identify a representative network of three to five cancer-treating hospitals (tertiary level) and two to three district/sub-district hospitals (secondary level), depending upon the geographical size of the region. The questionnaire was administered through an online portal. Descriptive statistics were used to analyse and present the final survey results.

Key findings

- Over two-thirds of the government tertiary hospitals had referral linkages with lower-tier non-childhood cancer-treating facilities; however, such links were seen in less than half (45.7%) of the private tertiary hospitals.
- Childhood cancer care services were provided at over one-third (39.1%) of the Secondary level hospitals, which was higher in private (56.5%) than public (32.8%) hospitals.
- A dedicated paediatric oncology department was available in less than half of the public and private tertiary hospitals.
- The majority of the tertiary level hospitals had supportive care facilities, including blood banks, nutritional rehabilitation, physiotherapy, psychological counselling and parental education. However, facilities for hospice care were available in less than half of the hospitals.
- Over three quarters (76.6%) of the public tertiary hospitals adopted a multidisciplinary team approach for childhood cancer treatment, compared to 35% of the private hospitals.
- More than 90% of the tertiary hospitals had facilities for histopathology; however, a lower proportion of public tertiary hospitals had facilities for immunohistochemistry, flowcytometric immunophenotyping, cytogenetics, tumour markers and fluorescence in situ hybridization (FISH), which about half of the public tertiary hospitals provided referral services for those investigations.
- Over 80% of the tertiary hospitals had facilities for CT scans, MRI and ultrasonograms; however, the availability of bone scans and PET scans was lower, especially in public sector hospitals.
- Less than a quarter (20.7%) of the public hospitals had facilities for Haemopoietic Stem Cell Transplantation (HSCT) compared to half of the private hospitals (54.2%).
- At public tertiary hospitals, less than half of the hospitals had a pediatric oncologist (48%), pediatric oncosurgeon (14.2%), pediatric intensivist (38.9%), medical oncologist (49.3%) and palliative care physician (37.6%).
- Nurses specialized in pediatric cancer, and palliative care was available in less than 50% of the public and private tertiary hospitals.
- Among palliative care medications, methadone and morphine oral liquid stocks were available in less than 30% of the public, private, and tertiary hospitals. A larger proportion

of targeted therapies were not available at the public tertiary hospitals compared to private hospitals.

- A higher proportion of private secondary level hospitals had cancer-treating medications in stock among the secondary hospitals.
- The most commonly adopted financing mechanism comprised the Ayushman Bharat Scheme at public tertiary level hospitals and secondary level public hospitals and ESI/State specific schemes at private tertiary hospitals.
- Only about a third of the tertiary hospitals had active pediatric oncology clinical research programs at Hospital or pediatric oncology unit/ward
- For public tertiary and secondary level hospitals, the major challenges faced included shortage of human resources, lack of beds, shortage of equipment and lack of physical space for extending facilities. Shortage of human resources was an essential concern for private tertiary and secondary hospitals.
- The most frequent challenge patients and their caregivers faced regarding treatment was treatment denial and treatment abandonment, for which financial constraints were the most commonly cited reason.
- The delivery of childhood cancer care services at over half of the tertiary hospitals was impacted by the COVID pandemic resulting in a decreased diagnosis of new pediatric cases in a majority of the hospitals and increased rates of treatment abandonment.

The situational analysis of childhood cancer care services in India reiterates a skewing in the availability of childhood cancer care services at the tertiary level of health care. Most childhood cancers are associated with non-modifiable risk factors. The key to a better prognosis and favourable outcomes is early and accurate diagnosis and timely initiation of effective treatment. The need of the hour is to formulate a childhood cancer policy that will enable timely diagnosis, treatment, supportive care and follow-up through well-defined care pathways.

A. Definitions

Availability of diagnostic and treatment services: Physical presence of the laboratory services, radiologic/nuclear investigation and specific procedures and treatment interventions for cancer. For the available services, service utilization was measured through tracer items that included average time to avail services, referral to other centres, and the means opted for making the referral.

Capacity building: Training and technical assistance that builds resources enabling communities to deliver evidence-based interventions

Cancer care facilities and coordination: Ability of the health facility to offer either diagnosis or treatment for childhood cancers in the hospital. The capacity to provide this was measured through tracer items that included availability of departments and average waiting time for getting an appointment, supportive care facilities, social support, multidisciplinary team approach, treatment decision and patient follow-up.

Continuing medical education: A continuing education process to learn about new and developing areas of a field, upgrade and maintain professional competence.

Chemotherapy: Type of cancer-treating modality that uses one or more anti-cancer medicines to halt the growth of cancer cells, either by killing or stopping the cells from dividing. Chemotherapy may be given orally or parentally, depending on the type and stage of cancer. It may be given alone or with other treatments, such as surgery, radiation therapy, or biologic therapy.

Financing of treatment: mode adopted for paying for childhood hood cancer care. This included government financing, state-specific financing, individual private insurance and employment-based group private insurance.

A formal agreement for patient referral: A signed acknowledgement between two health care facilities in which they agree to attend to a referred patient and coordinate patient care between the two facilities.

Health insurance is an agreement between the insured and the insurer that is effective when an adverse health event occurs. The insurer will reimburse the compensation either to the insured person or the health service provider.

Information, Education and Communication (IEC) is a "public health approach that aims to change or reinforce health-related behaviours in a defined target audience, concerning a specific problem using varied communication methods".

A medical oncologist is the "primary health care provider for an individual diagnosed with cancer. The doctor specialises in diagnosing and treating cancer".

The medical record system refers to the "availability of digital versions of the patient paper charts at the hospitals".

Multi-speciality Hospital offers "tertiary care and specialized care in multiple specialities through an expert team of medical specialists and allied health personnel".

Nutritional Rehabilitation Centers are care units where "severely acute malnourished (SAM) children below five years are admitted with their mothers/caregivers for treatment, stabilization and rehabilitation".

Physical infrastructure, equipment and medicines: Physical infrastructure relevant for managing childhood cancer services at the Hospital included the following services as broad categories; beds, systemic therapy and supportive care.

The medications were broadly classified as a medicine for palliative/supportive care, medication for other symptoms common in palliative care and supportive drugs. Each medication was checked for availability, stock-outs per year, and procurement.

Palliative care is a specialized area of medical care that aims to relieve patients from pain and other cancer-related symptoms.

Service availability: Physical presence of health delivery services, including health infrastructure, essential health personnel and features of service utilization.

Secondary level Hospital: Refers to hospitals at the second tier of the health system, which attend to patients referred from health centres at the primary level.

Treatment guidelines encompassed the recommended guidelines adopted at each hospital for leukaemia, lymphoma, brain tumours, neuroblastoma, Wilms tumour and bone cancer. It also included written protocols for administering chemotherapy, managing febrile neutropenia, and central venous access devices.

Tumour board meeting includes a group of doctors and other health care providers with different specialities that meet regularly at the hospital to discuss cancer cases and share knowledge.

Telemedicine: Health care services delivery using technologies for information and communication employed by health care providers in places where distance is critical. It helps to exchange meaningful information for the prevention, diagnosis and treatment of disease and injuries, enables research and evaluation, and helps in the continuing education of health care providers, all in the interests of promoting the health of individuals and communities."

Tertiary level hospital: Includes hospitals at the third tier of the health system. Specialized treatment and care are provided, usually based on a referral from health facilities at the primary and secondary levels.

Treatment abandonment: Failure to complete treatment when the disease can be effectively controlled or missing therapy for a defined period affects disease prognosis.

Treatment denial: Non-acceptance or refusal to undergo treatment that the attending health care provider advises.

B. Abbreviations

AAR	age-adjusted rate
AARpm	age-adjusted rate per million
CBC	complete blood count
CGHS	Central Government Health Scheme
CNS	central nervous system
CSO	civil society organization
CT	computed tomography
ESI	Employees' State Insurance
FISH	fluorescence in situ hybridization
FNB	fellowship of the national board
HBCR	hospital-based cancer registry
HIC	high-income countries
HLA	human leukocyte antigen
HSCT	haemopoietic stem cell transplantation
IAP	indian academy of pediatrics
IMCI	integrated management of childhood illness
IEC	information education communication
LIC	low-income countries
MIBG	iodine-123 meta-iodobenzylguanidine
MRI	magnetic resonance imaging
NCD	noncommunicable Disease
NGO	non-governmental organization
NPCDCS	National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke
OOP	out-of-pocket
PBCR	Population Based Cancer Registry
PET CT	positron emission tomography and computed tomography
PHO	pediatric hemato-oncology
PICU	paediatric intensive care unit
PM-JAY	Ayushman Bharat Pradhan Mantri Jan Arogya Yojana
RBSK	Rashtriya Bal Swasthya Karyakram
RDBMS	relational database management systems
RT PCR	real-time polymerase chain reaction
SARA	service availability and readiness assessment
SIOP	societe internationale d’oncologie pediatrique
WHO	World Health Organization

Figures

33	Proportion of secondary level facilities where social worker accompanies the referred patient (%)
34	Average waiting time to get an appointment according to departments at public tertiary hospitals
35	Average waiting time to get an appointment according to departments at private tertiary hospitals
36	Availability and mode of referral services for supportive care services that are not available at the hospital at public tertiary hospitals
37	Availability and mode of referral services for supportive care services that are not available at the hospital at private tertiary hospitals
38	Availability and mode of referral services for supportive care services that are not available at the hospital at private tertiary hospitals
39	Average waiting time to avail of an appointment at public secondary hospitals
40	Average waiting time to avail of an appointment at private secondary hospitals
41	Average waiting time to avail of an appointment at NGOs/charitable hospitals
42	Average waiting time for radiologic and nuclear medicine services at tertiary hospitals
43	Availability and mode of referral services for radiologic and nuclear services that are not available at the tertiary hospital
44	Average waiting time for diagnostic services at public secondary hospitals
45	Average waiting time for diagnostic services at private secondary hospitals
46	Average waiting time for diagnostic services at NGO/charitable hospitals
47	Average waiting time to avail of specified treatment procedures at a public tertiary hospital
48	Average waiting time to avail of specified treatment procedures at a private tertiary hospital
49	Average waiting time to avail of specified treatment procedures at NGO/charitable tertiary hospital
50	Means for seeking consultation from specialists not available in the tertiary hospital
51	Means for seeking consultation from paramedical specialists not available in the tertiary hospitals
52	Availability of drugs used in palliative care in public tertiary hospitals
53	Costing of drugs used in palliative care in public tertiary hospitals
54	Availability of drugs used in palliative care in private tertiary hospitals
55	Costing of drugs used in palliative care in private tertiary hospitals
56	Availability of drugs used in palliative care in NGO/charitable tertiary hospitals
57	Costing of drugs used in palliative care in NGO/charitable tertiary hospitals
58	Availability of drugs used in targeted therapies in tertiary hospitals
59	Costing of drugs used in targeted therapies in tertiary hospitals
60	Availability of antineoplastic drugs in public tertiary hospitals
61	Costing of antineoplastic drugs in public tertiary hospitals
62	Availability of antineoplastic drugs in private tertiary hospitals
63	Costing of antineoplastic drugs in private tertiary hospitals
64	Availability of antineoplastic drugs in NGO/charitable tertiary hospitals
65	Costing of antineoplastic drugs in NGO/charitable tertiary hospitals

Tables

Chapter 1: Introduction

The burden of childhood cancer in India

Childhood cancer is a physically and cognitively debilitating disease, leading to short-term fatal consequences or long-term adverse effects of prolonged illness and treatment. According to the recent NCRP report based on data from hospital-based cancer registries (HBCRs'), Childhood cancers (0-14 years of age) comprise 4% of all reported cancers in India. The proportion of children affected may be higher owing to "missed cases" due to low coverage, lack of awareness, delayed diagnosis and a fledgling electronic referral system.

The age-adjusted incidence rate (AAR) of childhood cancer (0-14 years) worldwide is 140.6 per million person-years. The age-adjusted incidence rate per million (AARpm) is an important metric to monitor the new cancer cases in a defined population. There are variations among different parts of the country, with New Delhi showing the highest AARpm among boys (203.1) and girls (125.4). From southern India, Chennai ranks second among boys (146.7) and third among girls (52.7) in childhood cancer incidence. In the northeast, the AARpm was the highest in Aizawl among boys and girls (133.9 and 91.4, respectively).

A noticeable difference in the incidence rates between genders is observed in countries worldwide and India. There is a higher incidence in males compared to females, which is stark in low-income countries (LIC) compared to high-income countries (HIC).

The most common primary sites of pediatric cancers include the 3B's, namely "blood, bone, brain''. Some of the most common malignancies include leukaemia, lymphoma, central nervous system (CNS) tumours like glioma and medulloblastoma, tumours of the bone and soft tissue like Ewing's sarcoma, rhabdomyosarcoma and "blastomas" that affect different solid organs. Childhood leukaemia is followed by lymphomas which rank second in their prevalence after leukaemia. Unlike in the west, Hodgkin's lymphoma is more prevalent than non-Hodgkin's lymphoma in India.

In contrast to the adult counterparts, childhood cancer variants may be characterized by atypical or nonspecific disease presentation and non-traditional pathognomonic disease markers, which calls for specialized training programs in paediatric oncology for early disease recognition and effective implementation of the treatment protocol.

The long-term physical and psychological effects of the treatment can become lifelong stressors. The physical effects of childhood cancer treatment could result in frequent hospitalizations among survivors in adult life; epilepsy, pituitary hypofunction and abnormal menstruation, non-infective enteritis, colitis, pneumonia and upper respiratory infections. They can also be affected by psychological stress due to physical effects (amputation, hair loss). Therefore, it is imperative to understand that the burden of childhood cancer could be long-term. Special attention needs to be given to the physical and psychological stressors to improve the quality of life of these patients and prevent long-term morbidity.

Childhood cancer care services

The first paediatric oncology unit in India started in the 1960s, and the number of such units has increased since the 1980s. A national survey of childhood cancer services was conducted in 1988. In 50% of the surveyed centres, paediatric oncology cases were handled by adult oncologists, and only 10% of the centres had paediatric oncologists primarily trained abroad. A scarcity of specialists in paediatric oncology could be attributed to a lack of training programmes in this area. However, the last decade has seen an improvement in paediatric oncology education with the initiation of fellowship and super speciality courses for trained paediatricians and short-term training programmes for primary care paediatricians and nurses, facilitating early recognition and referral to higher education centres.

Most paediatric cancer care centres in India are in urban areas, leading to delayed access by the rural population. It is seen that children with cancer often present with an advanced-stage disease which worsens the outcome. The lack of sturdy referral systems is one of the reasons for late-stage presentations and delayed diagnosis.

For early treatment initiation, accessibility to anticancer drugs and availability of adequate drug stock are essential. In addition to the essential medicine list for children published by the World Health Organization (WHO), a working group was created by the Societe Internationale d'Oncologie Pediatrique (SIOP) to identify the essential medications for childhood cancers in low-income countries, taking into account the logistics of accessibility and accountability. A total of 51 drugs spanning three categories of antineoplastic, antimicrobials and supportive care medications were included. Such lists can guide the development of nation-specific essential medicine lists, which need to be periodically updated and improved based on updated treatment guidelines. India published 'The national essential drugs list' in 1996, later revised and renamed 'The national list of essential medicines, which was last updated in 2015. Although

most childhood cancer drugs have been included, as enlisted in the essential medicine list for Children by WHO, it does not mention paediatric formulations and dosage. The states of India have drawn up their list of essential medicines based on their patterns of cancer epidemiology in adults.

Government hospitals offer high-quality medicines for childhood cancer or are highly subsidised. The central and state governments launched health insurance schemes to provide financial packages that offer coverage for various childhood cancer care health expenditures. The Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PM-JAY) was launched in 2018 to provide financial assistance for secondary and tertiary care hospitalization. Oncology benefit packages are provided in four specialities: medical oncology, surgical oncology, radiation oncology, and paediatric cancer.

Lack of essential infrastructure for diagnosing and treating childhood cancer is one of the major causes of treatment abandonment, ranging between 10-63%. A survey of the diagnostic facilities in low-income countries revealed significant gaps in the availability of essential laboratory diagnostic infrastructure, which hinder an accurate diagnosis in suspected paediatric oncology cases.

The rationale of this study

The role of programmes and policies in childhood cancer control cannot be stressed enough. Currently, the national-level programmes and policies mainly focus on adult cancer and related cancer risk factors primarily implemented through the NPCDCS. There is, however, a need for a well-defined evidence-based national-level policy dedicated to childhood cancer.

Developing evidence-based policies for childhood requires a situational analysis of childhood cancer services' present state. Such interventions will enable high-quality care within limited health care resources, culminating in improved survival and quality of life of pediatric cancer patients in India.

Aim and Objectives

Aim:

To assess the status of childhood cancer care services in India

Objectives:

Primary: To assess the

(i) Availability of childhood cancer care services

(ii) Facility preparedness, treatment-related practices and referral linkages in childhood cancer care

(iii) Barriers and facilitators in the provision of childhood cancer care services

Chapter 2: Methodology

The situational analysis was conducted using a cross-sectional survey design.

Study setting and participants:

(i) Secondary and tertiary cancer hospitals in 26 states and 4 Union Territories.

(ii) State nodal officers of the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke.

(iii) Civil society organizations engaged in cancer care

Study procedures:

a) Health facility survey: The data collection method was based on the hub and spoke model. A nodal childhood cancer treating hospital in each state or union territory was identified as the 'hub centre' to coordinate the survey in the state. The nodal hospital was asked to identify a representative network or the 'spoke centres' of the major three to five cancer treating hospitals (tertiary level) and two to three district/sub-district hospitals (secondary level), as seen in Fig. 1. A pre-tested questionnaire, consisting of questions related to the organizational infrastructure such as type of oncology services, health workforce, equipment, treatment and referral protocols, and use of treatment guidelines as relevant for childhood cancels service availability, was used as a study tool. The study tool questionnaire was based on the WHO Service Availability and Readiness Assessment (SARA), a health facility assessment tool designed to assess and monitor service availability and the WHO list of priority medical devices for cancer management. The questionnaire was administered through an online portal to the hospitals that consented to participate in the survey. Participating hospitals were apprised of the codal formalities and were oriented to the questionnaire. Login credentials for the participating hospitals of a particular state were provided to the nodal hospital of that state. Manual entry of survey responses was permitted in hospitals without facilities for electronic data entry. Once the survey forms were completed, the nodal hospitals reviewed and submitted the survey responses (Fig. 2). The survey forms were thoroughly evaluated for missing data throughout the data entry and submission process. The particular hospitals were informed promptly via email with an attached document containing the missing data fields specific to those hospitals. Following that, reminder calls were made to furnish missing data.

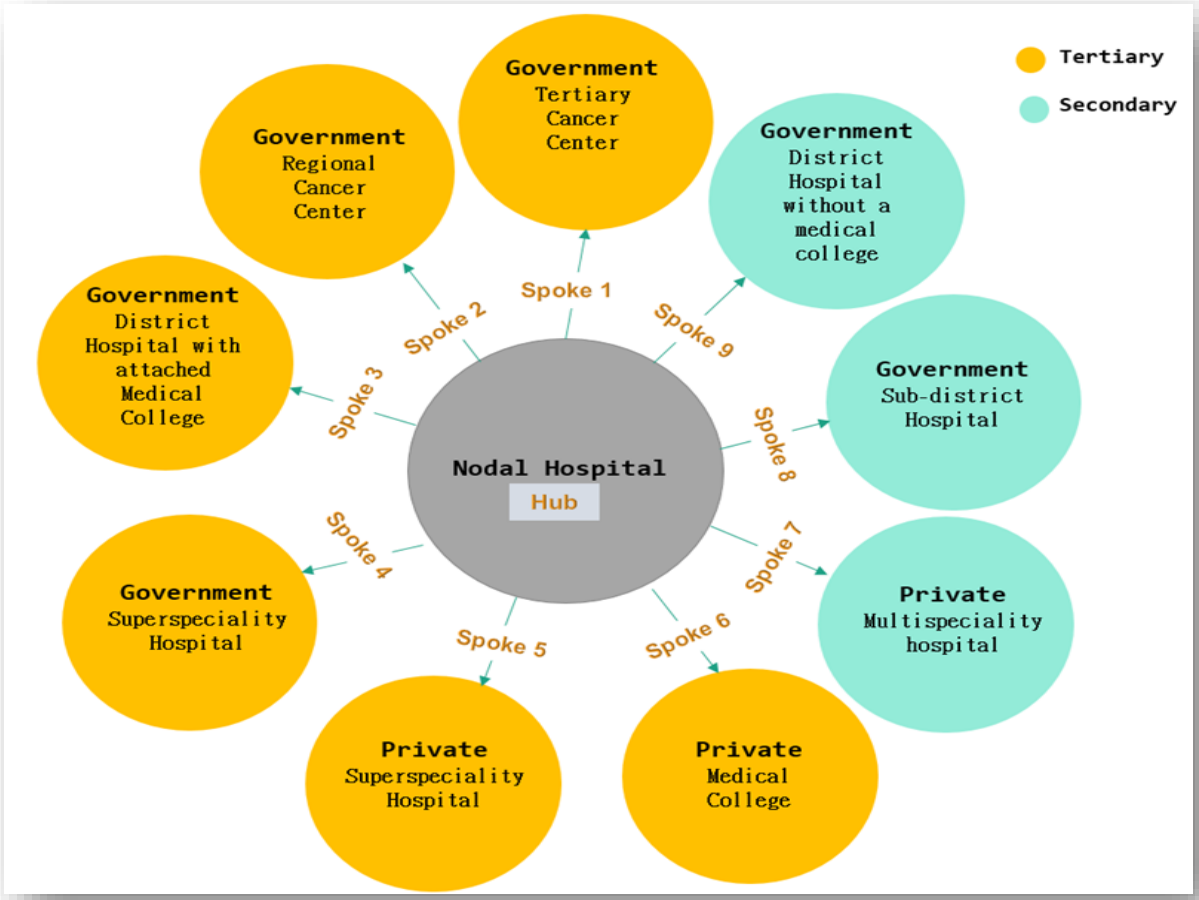

Fig. 1 - Representative network of participating hospitals

b) Survey among state nodal officers and civil society organizations: The study proforma included questions on the barriers and facilitators of childhood cancer care and suggested strategies to enhance childhood cancer care services in India.

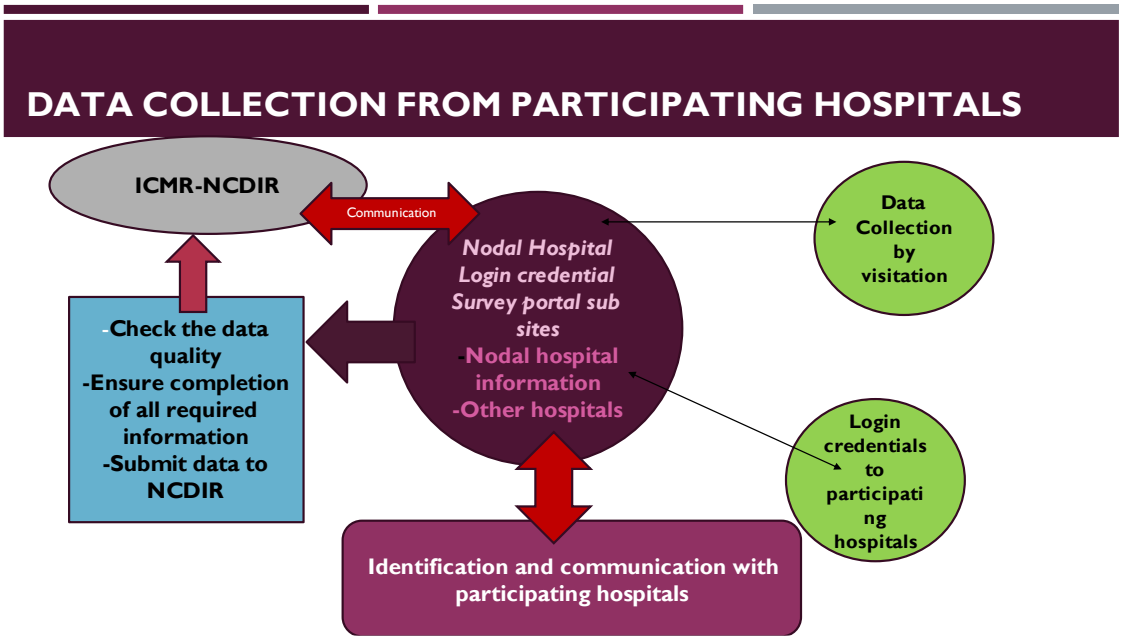

Fig. 2 – Data collection from participating hospitals

Data analysis

Data collected was stored in a structured way in an RDBMS (relational database management system). Data analysis was done using Microsoft Excel. Descriptive statistics was used primarily to present the health service status and data on childhood cancer care services in proportions and mean. Responses to open-ended questions were analysed and presented as proportions.

Chapter 3: Results

Part A. Status of childhood cancer care services at tertiary and secondary level hospitals

3.1 Participation rates

A total of 137 tertiary level hospitals, 101 secondary level hospitals, 26 state nodal officers/NPCDCS officers and 13 civil society organizations/non-governmental organizations (CSOs/NGOs) had been approached for their participation, out of which 137 tertiary level hospitals, 92 secondary level hospitals, 16 State nodal officers/NPCDCS officers and nine civil society organizations/non-governmental organizations (CSOs/NGOs) consented to participate.

3.2 Type of hospitals

Table 1

Type of hospital		Major source of financial support							
		Government		Private		Charitable/NGO		N	%
		n	%	n	%	n	%		
Tertiary level hospitals	Medical college hospital	53	68.8	11	31.4	6	24.0	70	51.1
	Super speciality (oncology)	12	15.5	8	22.8	12	48.0	32	23.4
	Multispecialty with dedicated oncology unit	12	15.5	16	45.7	7	28.0	35	25.5
	Total number of tertiary hospitals	**77**	**56.2**	**35**	**25.5**	**25**	**18.2**	**137**	**100**
Secondary level hospitals		**64**	**69.5**	**23**	**25.0**	**5**	**5.4**	**92**	**100**

3.3 Average number of childhood cancer cases treated every year

3.3.1 Tertiary level hospitals: Average number of new cases of childhood cancers treated per year (2018-2020) at tertiary hospitals

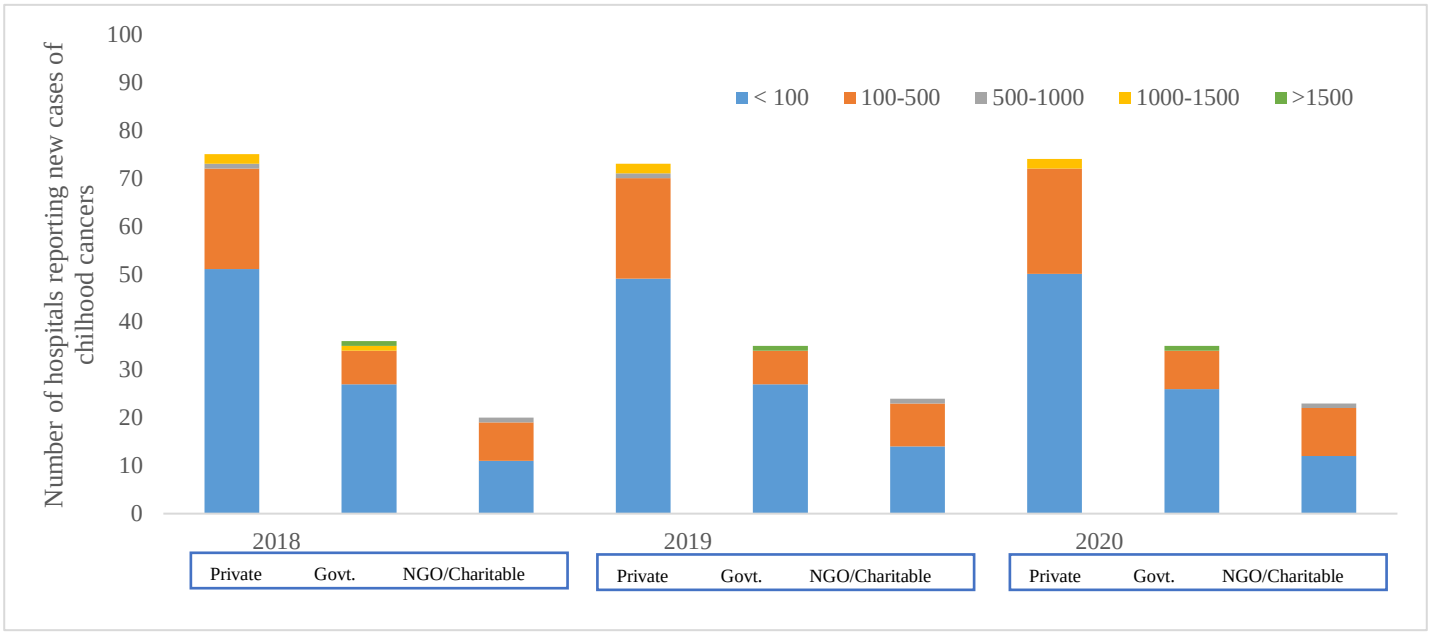

Fig. 3

3.3.2 Average number of childhood cancer cases treated per year (average over the last three years) at secondary hospitals

Out of the 92 secondary level hospitals, 36 hospitals (39.1%) were providing childhood cancer care services

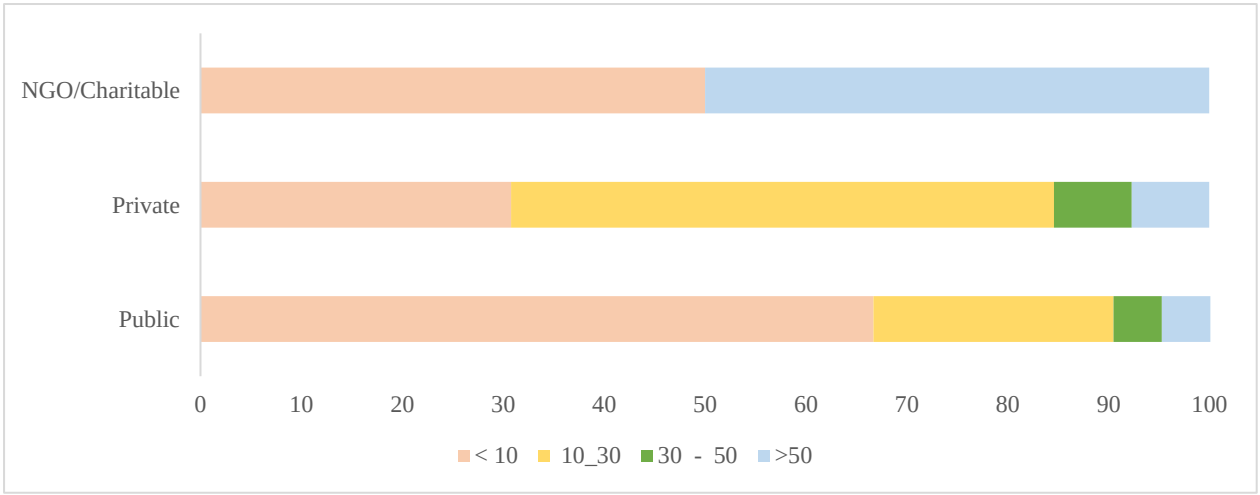

Fig. 4

3.4 Referral linkages

3.4.1 Tertiary level hospitals

3.4.1.1 Percentage of tertiary level hospitals with referral linkages with lower tier health facilities

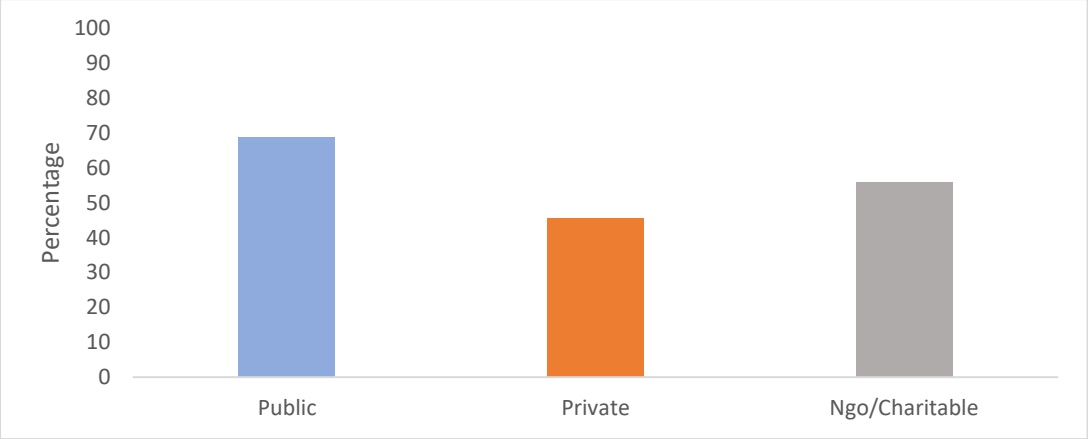

Fig. 5

3.4.1.2 Means of obtaining referral of patients from lower tier health facilities.

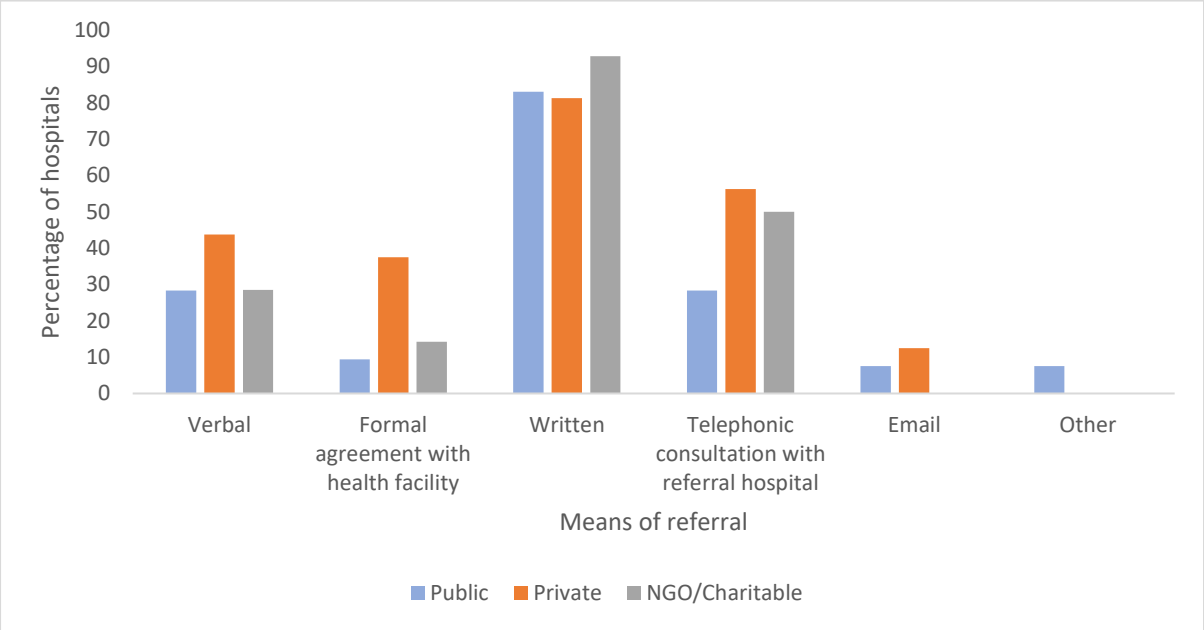

Fig. 6

3.4.2 Secondary-level hospitals

3.4.2.1 Private/public/charitable hospitals having referral linkages with cancer treating (tertiary) facilities

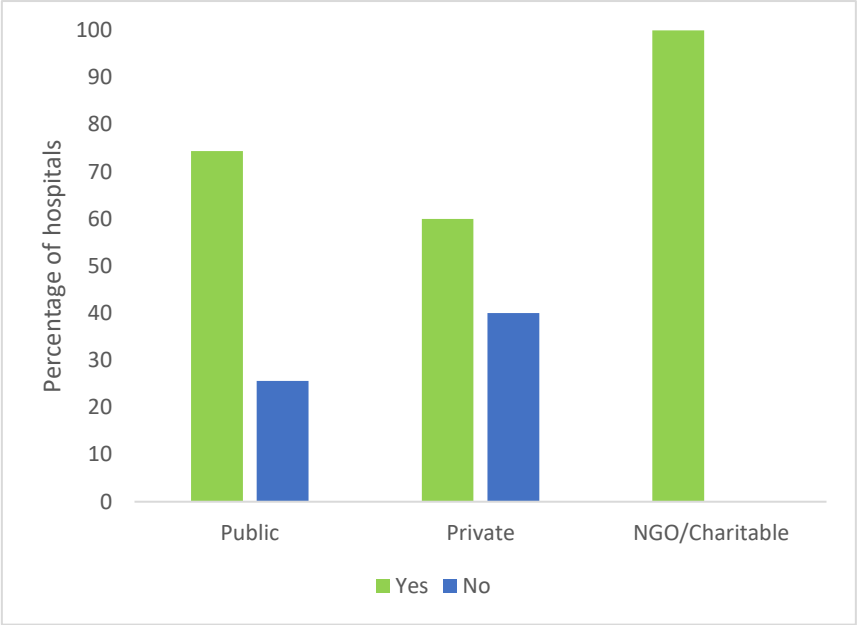

Fig. 7

3.4.2.2 Means of referring patients to tertiary level cancer treating centres.

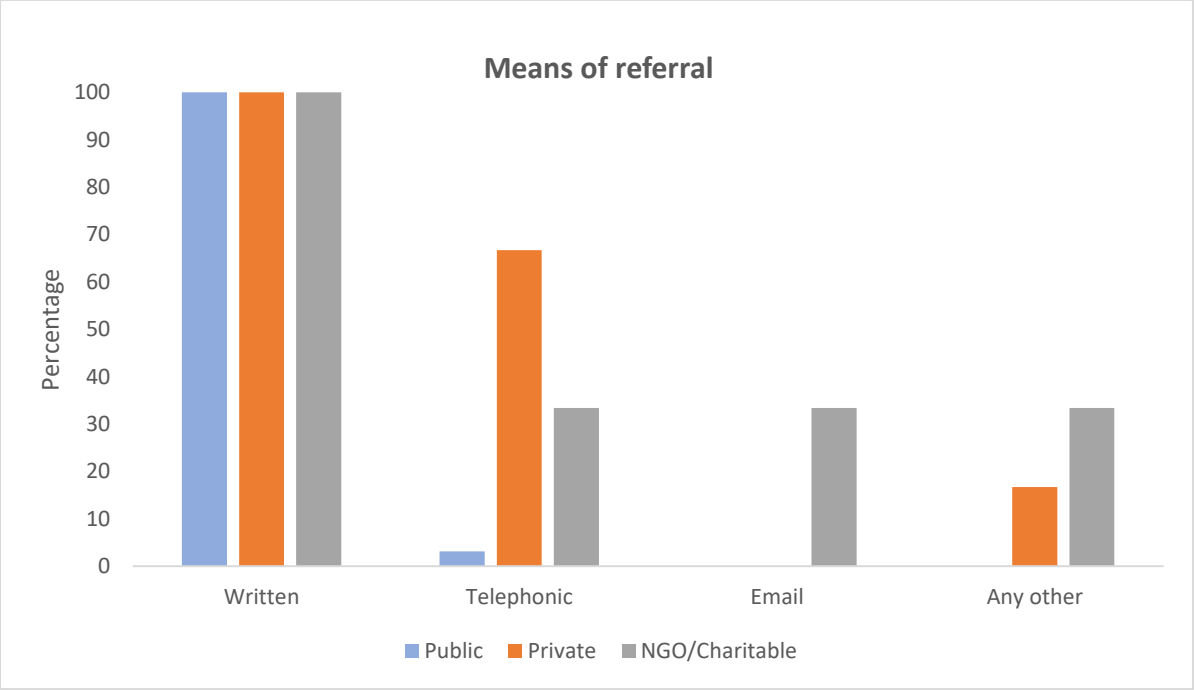

Fig. 8

3.4.2.3 Private/public/charitable hospitals having referral linkages with primary non-cancer treating facilities

Table 2

Referral linkage with primary level/non-cancer treating health facilities						
	Public (n = 64)		Private (n = 23)		Charitable (n = 05)	
	n	%	n	%	n	%
Yes	39	60.9	12	52.1	2	40
No	25	39.1	11	47.9	3	60
Mechanism of obtaining referred cases						
	Public (n = 39)		Private (n = 12)		Charitable (n = 02)	
	n	%	n	%	n	%
Written	37	94.8	12	100	2	100
Telephonic	4	10.2	7	58.3	0	0
Any other	2	5.1	0	0	0	0

3. 5 Cancer care departments and care coordination

3.5.1 Tertiary level hospitals

3.5.1.1 Availability of childhood cancer treatment-related departments, according to funding

Table 3

S. No.	Department	Public n = 77		Private n = 35		NGO/charitable n = 25	
		n	%	n	%	n	%
1	Pediatric oncology	32	41.6	17	48.6	16	64.0
2	Medical oncology	35	45.5	22	62.9	15	60.0
3	Radiation oncology	52	67.5	24	68.6	17	68.0
4	Surgical oncology	41	53.2	24	68.6	17	68.0
5	Pediatric medicine	60	77.9	24	68.6	16	64.0
6	Medicine	47	61.0	20	57.1	11	44.0
7	Haematology	33	42.9	20	57.1	13	52.0
8	Pediatric surgery	48	62.3	20	57.1	11	44.0
9	surgery	55	71.4	19	54.3	11	44.0
10	Ophthalmology	50	64.9	21	60.0	9	36.0
11	Musculoskeletal oncologist	7	9.1	7	20.0	9	36.0
12	Orthopaedics	61	79.2	23	65.7	12	48.0
13	Neurosurgery	47	61.0	23	65.7	10	40.0

S. No.	Department	Public		Private		NGO/charitable	
		n = 77		n = 35		n = 25	
		n	%	n	%	n	%
14	Radiology	66	85.7	31	88.6	22	88.0
15	Nuclear medicine	27	35.1	18	51.4	11	44.0
16	Pathology	71	92.2	31	88.6	24	96.0
17	Palliative medicine	37	48.1	20	57.1	18	72.0

3.5.1.2 Availability of supportive care facilities

Table 4

S. No.	Supportive care facilities	Public		Private		NGO/charitable	
		n = 77		n = 35		n = 25	
		N	%	n	%	n	%
1.	Blood bank	72	93.5	30	85.7	18	72.0
2.	Nutritional rehabilitation	54	70.1	32	91.4	20	80.0
3.	Physiotherapy	72	93.5	34	97.1	21	84.0
4.	Psychological counselling	61	79.2	27	77.1	22	88.0
5.	Parental education	58	75.3	25	71.4	17	68.0
6.	Occupational therapy	39	50.6	19	54.3	14	56.0
7.	Hospice care	26	33.8	13	37.1	6	24.0
8.	Dental care	69	89.6	32	91.4	14	56.0
9.	Play therapy	29	37.7	10	28.6	7	28.0
10.	Growth and development	60	77.9	29	82.9	16	64.0
11.	Immunization	66	85.7	32	91.4	16	64.0
12.	Fertility preservation services	14	18.2	11	31.4	4	16.0
Social support							
13.	Social support	51	66.2	24	68.6	22	88.0
14.	Parental groups	29	37.7	14	40.0	14	56.0
15.	Accommodation/lodging for patients and caregivers	40	51.9	15	42.9	17	68.0

3.5.1.3 Multidisciplinary team approach

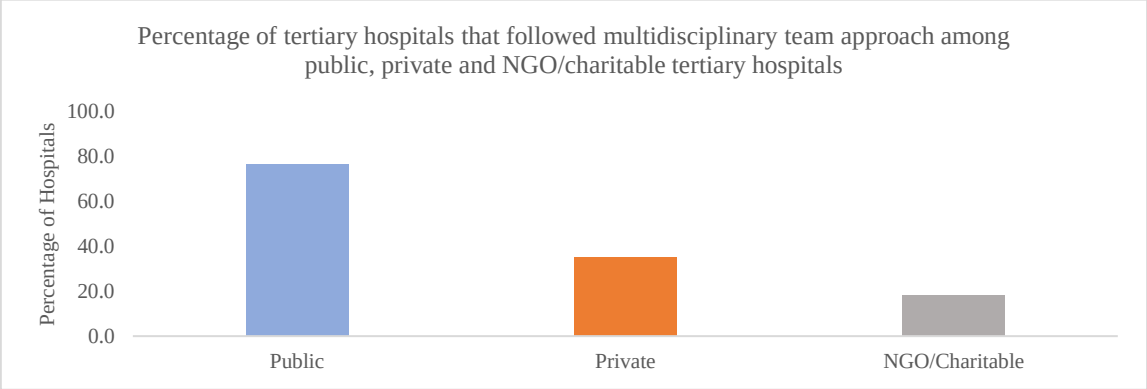

Fig. 9

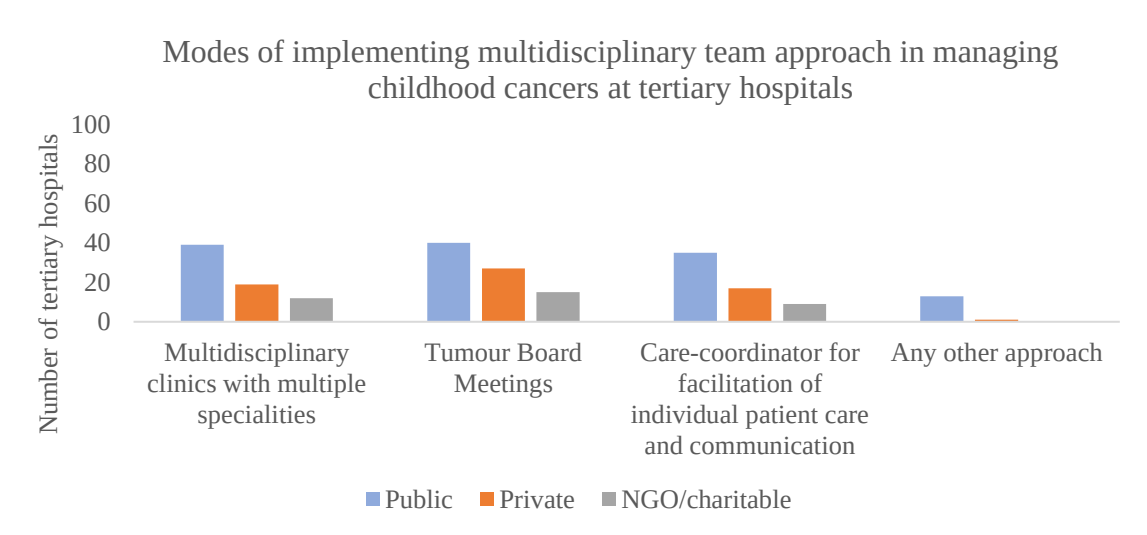

Fig. 10

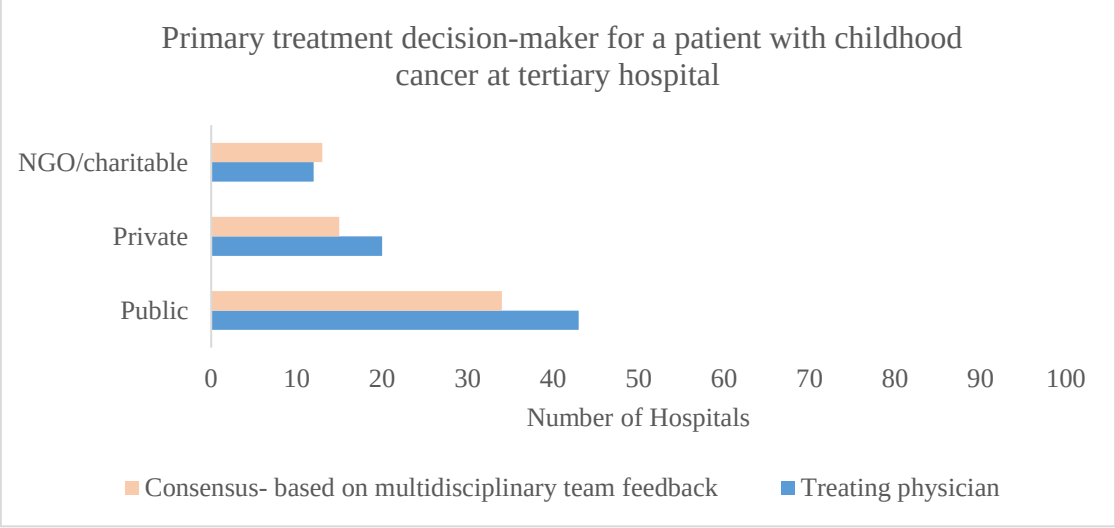

Fig. 11

3.5.1.4 Mechanism of follow-up of patients (apart from hospital visits)

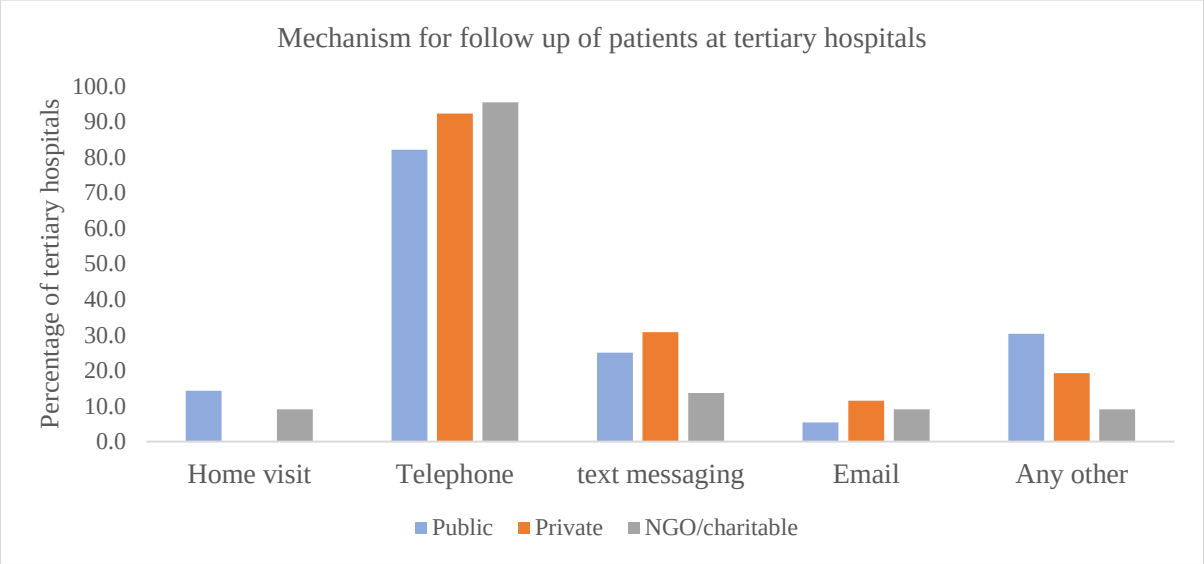

Fig. 12

3.5.2 Secondary-level hospitals

3.5.2.1 Availability of childhood cancer-treating facilities

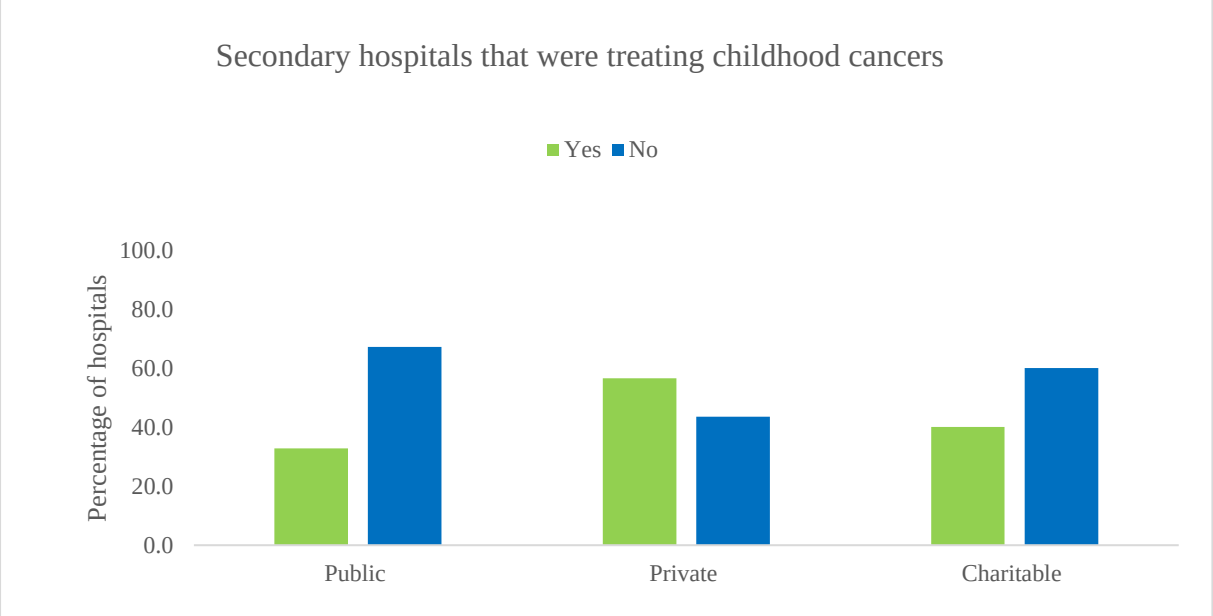

Fig. 13

3.5.2.2 Availability of departments for childhood cancer treatment

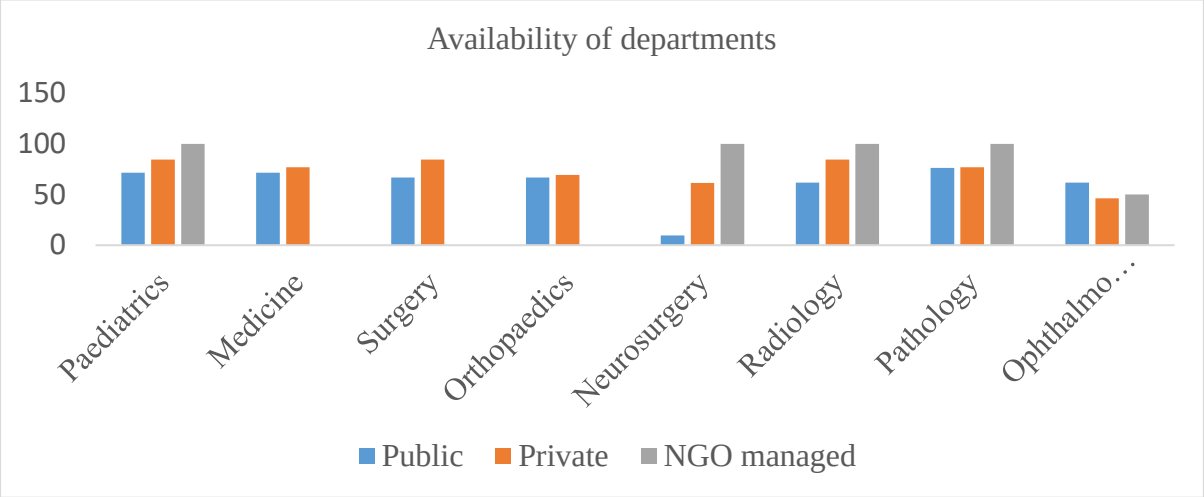

Fig. 14

3.5.2.3 Availability of supportive care facilities

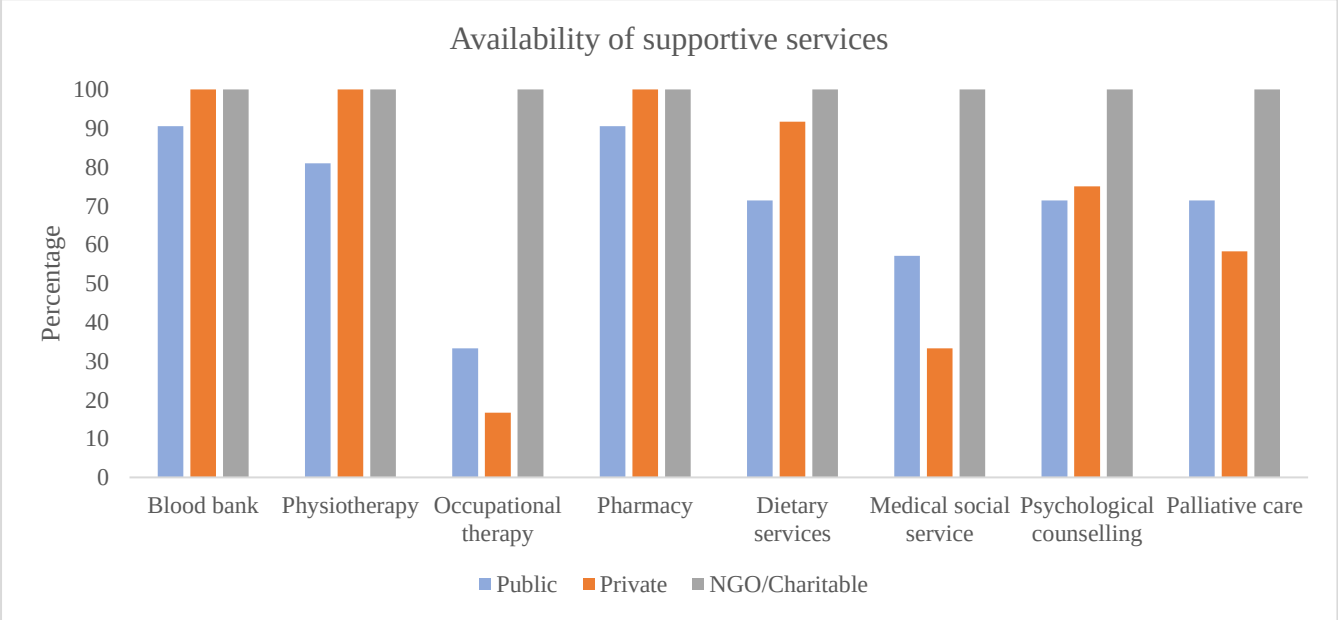

Fig. 15

3.6 Availability of diagnostic facilities

3.6.1 Tertiary hospitals

3.6.1.1 Availability of laboratory services – tertiary hospitals

Table 5

S. No.	Laboratory services	Public		Private		NGO/charitable	
		n = 77		n = 35		n = 25	
		n	%	n	%	n	%
1.	Histopathology	73	94.8	32	91.4	21	84.0
2.	Immunohistochemistry	45	58.4	25	71.4	17	68.0
3.	Flowcytometric Immunophenotyping	26	33.7	21	60.0	10	40.0
4.	Cytogenetics	15	19.4	12	34.2	8	32.0
5.	Tumour markers	48	62.3	29	82.8	19	76.0
6.	Fluorescence in situ hybridization (FISH)	15	19.4	10	28.5	7	28.0
8.	HLA typing	12	15.5	8	22.8	5	20.0
9.	Therapeutic drug monitoring	21	27.2	11	31.4	8	32.0

3.6.1.2 Availability of radiology and nuclear medicine services at tertiary hospitals

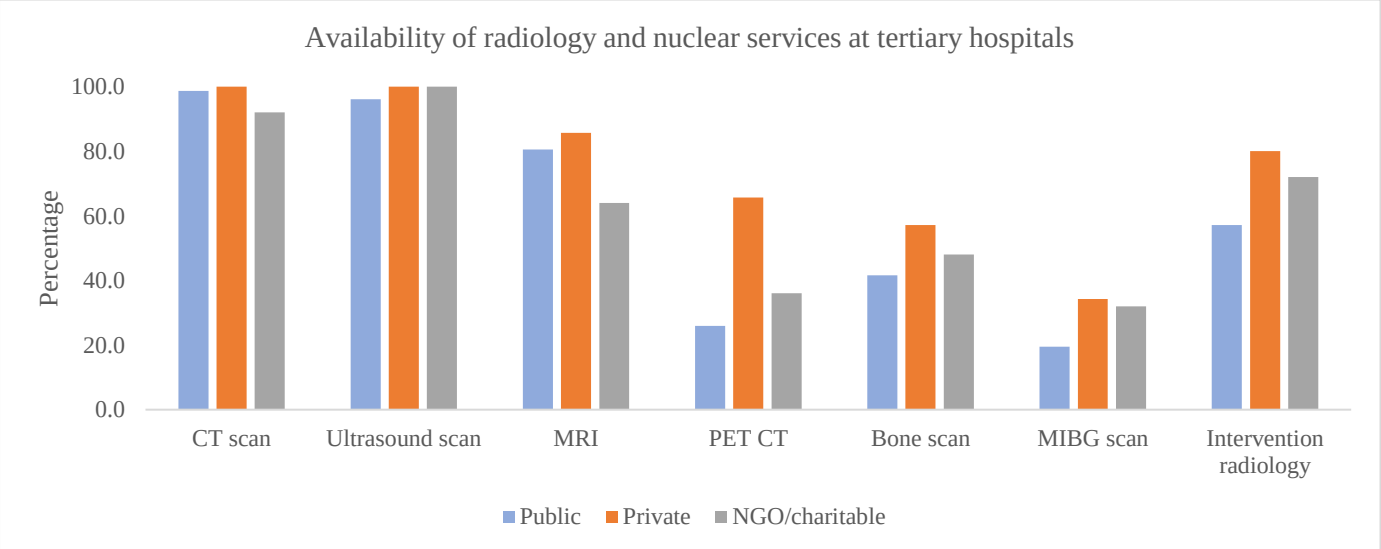

Fig. 16

3.6.2 Secondary hospitals: availability of diagnostic investigations

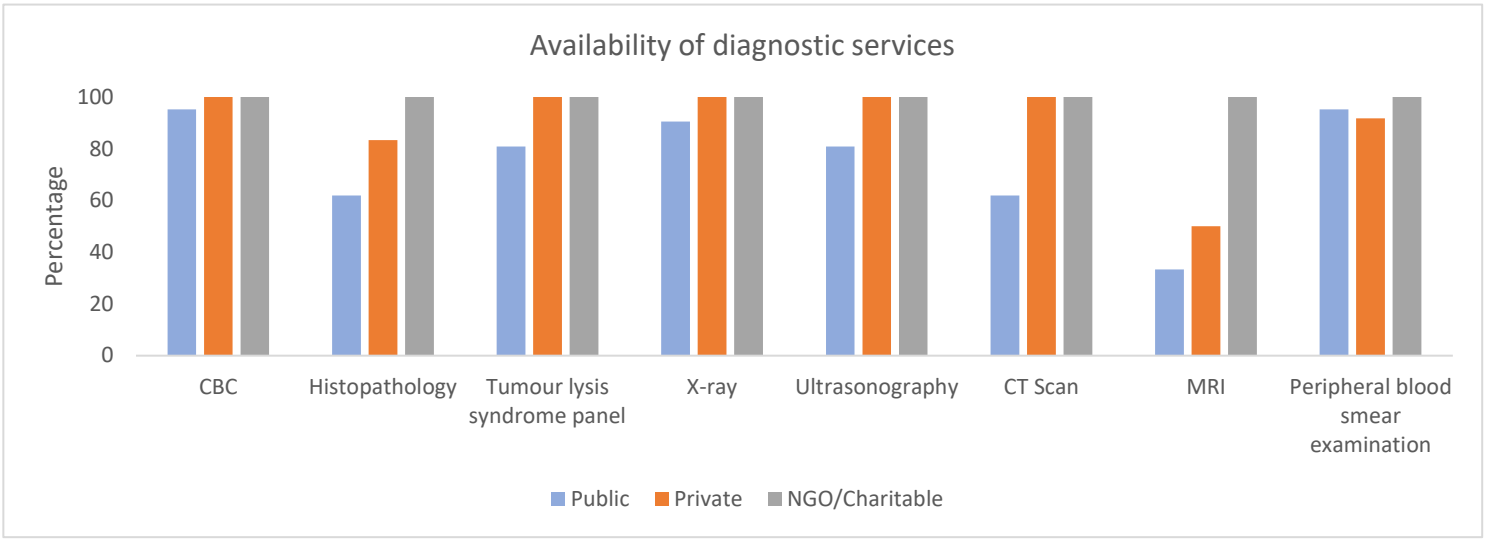

Fig. 17

3.7 Cancer-specific treatment procedures

3.7.1 Tertiary hospitals

3.7.1.1 Availability of specified procedures and treatment interventions

Table 6

Treatment intervention	Public (n = 77)		Private (n = 35)		NGO/charitable (n = 25)	
	n	%	n	%	n	%
Bone marrow aspiration	70	90.9	34	97.1	24	96.0
Bone marrow biopsy	67	87.0	34	97.1	24	96.0
Lumbar puncture	75	97.4	35	100	24	96.0
Central venous line	70	90.9	35	100	20	80.0
Small core biopsy	67	87.0	34	97.1	25	100
Excision biopsy	72	93.5	35	100	25	100
Drug infusion chemotherapy	60	77.9	29	82.9	22	88.0
Intrathecal chemotherapy	59	76.6	28	80.0	22	88.0
Immunotherapy	45	58.4	25	71.4	17	68.0
Cobalt-60 teletherapy	37	48.1	13	37.1	11	44.0
Linear accelerator	42	54.5	25	71.4	15	60.0
Brachytherapy	40	51.9	20	57.1	13	52.0
Haemopoietic stem cell transplantation (HSCT)	16	20.8	19	54.3	8	32.0
Focal therapy	16	20.8	11	31.4	9	36.0

3.7.1.2 Availability of written protocols

Table 7

Written protocol	Public (n = 77)		Private (n = 35)		NGO/charitable (n = 25)	
	n	%	n	%	n	%
Administration of chemotherapy	50	64.9	27	77.1	22	88.0
Management of febrile neutropenia	56	72.7	28	80.0	20	80.0
Management of central venous access devices	53	68.8	26	74.2	19	76.0

3.8 Human resources

3.8.1 Availability of human resources for childhood cancer care

Table 8

S. No.	Human Resources	Public				Private				NGO/charitable			
		Tertiary (n=77)	%	Secondary (n = 21)	%	Tertiary (n=35)	%	Secondary (n = 12)	%	Tertiary (n=25)	%	Secondary (n =1)	%
1.	Pediatric oncologist (Pediatrician working exclusively with childhood cancer)	37	48.0	-	-	19	54.3	-	-	16		-	-
2.	Paediatrician	-	-	6	28.6	-	-	11	91.7	-	-	1	100
3.	Pediatric oncosurgeon	11	14.2	3	14.3	6	17.1	7	58.3	7	28.0	1	100
4.	Pediatric surgeon	41	53.2	6	28.6	19	54.3	5	41.7	10	40.0	1	100
5.	Pediatric intensivist	30	38.9	-	-	15	42.9	-	-	10	40.0	-	-
6.	Medical oncologist	36	46.7	7	33.3	27	77.1	7	58.3	17	68.0	1	100
7.	Surgical oncologist	42	54.5	10	47.6	27	77.1	6	50.0	18	72.0	1	100
8.	Radiation oncologist	58	75.3	2	9.5	26	74.3	3	25.0	18	72.0	1	100
9.	Haematologist	38	49.3	12	57.1	21	60.0	3	25.0	16	64.0	1	100
10.	Palliative care physician	29	37.6	17	81.0	17	48.6	10	83.3	18	72.0	1	100
11.	Radiologist	74	96.1	2	9.5	34	97.1	7	58.3	23	92.0	1	100
12.	Neurosurgeon	54	70.1	16	76.2	26	74.3	8	66.7	12	48.0	1	100
13.	Orthopedician	68	88.3	18	85.7	28	80.0	10	83.3	19	76.0	1	100
14.	Pathologist	77	100.0	-	-	34	97.1	3	25.0	23	92.0	-	-
15.	Nuclear medicine specialist	29	37.6	17	81.0	24	68.6	11	91.7	11	44.0	1	100
16.	Anaesthetist	77	100.0	16	76.2	34	97.1	5	41.7	24	96.0	1	100
17.	Ophthalmologist	65	84.4	-	-	27	77.1	1	8.3	12	48.0	-	-

S. No.	Human Resources	Public				Private				NGO/charitable			
		Tertiary (n=77)	%	Secondary (n = 21)	%	Tertiary (n=35)	%	Secondary (n = 12)	%	Tertiary (n=25)	%	Secondary (n =1)	%
	Paramedical												
1.	Nurses trained in pediatric cancer	32	41.5	-	-	17	48.6	-	-	18	72.0	-	-
2.	Nurses	-	-	18	85.7			12	100.0			1	100
3.	Specialist palliative care nurse	28	36.3	-	-	12	34.3		0.0	13	52.0	-	-
4.	Cytotechnician	36	46.7	5	23.8	23	65.7	3	25.0	15	60.0	1	100
5.	Radiation therapy technician	54	70.1	3	14.3	26	74.3	6	50.0	17	68.0	-	-
6.	Radiographer	68	88.3	16	76.2	34	97.1	9	75.0	23	92.0	-	-
7.	Medical physicist	46	59.7	6	28.6	24	68.6	5	41.7	17	68.0	-	-
8.	Nuclear medicine technologist	26	33.7	-	-	24	68.6	2	16.7	11	44.0	-	-
9.	Physiotherapist	73	94.8	16	76.2	34	97.1	9	75.0	21	84.0	1	100
10.	Dietician	64	83.1	11	52.4	33	94.3	9	75.0	22	88.0	1	100
11.	Occupational therapist	32	41.5	6	28.6	17	48.6	2	16.7	13	52.0	1	100
12.	Social worker	59	76.6	9	42.9	24	68.6	2	16.7	20	80.0	1	100
13.	Counsellor	50	64.9	15	71.4	24	68.6	6	50.0	19	76.0	1	100

3.9 Physical infrastructure

3.9.1 Availability of physical infrastructure relevant for managing childhood cancer services at the tertiary hospitals

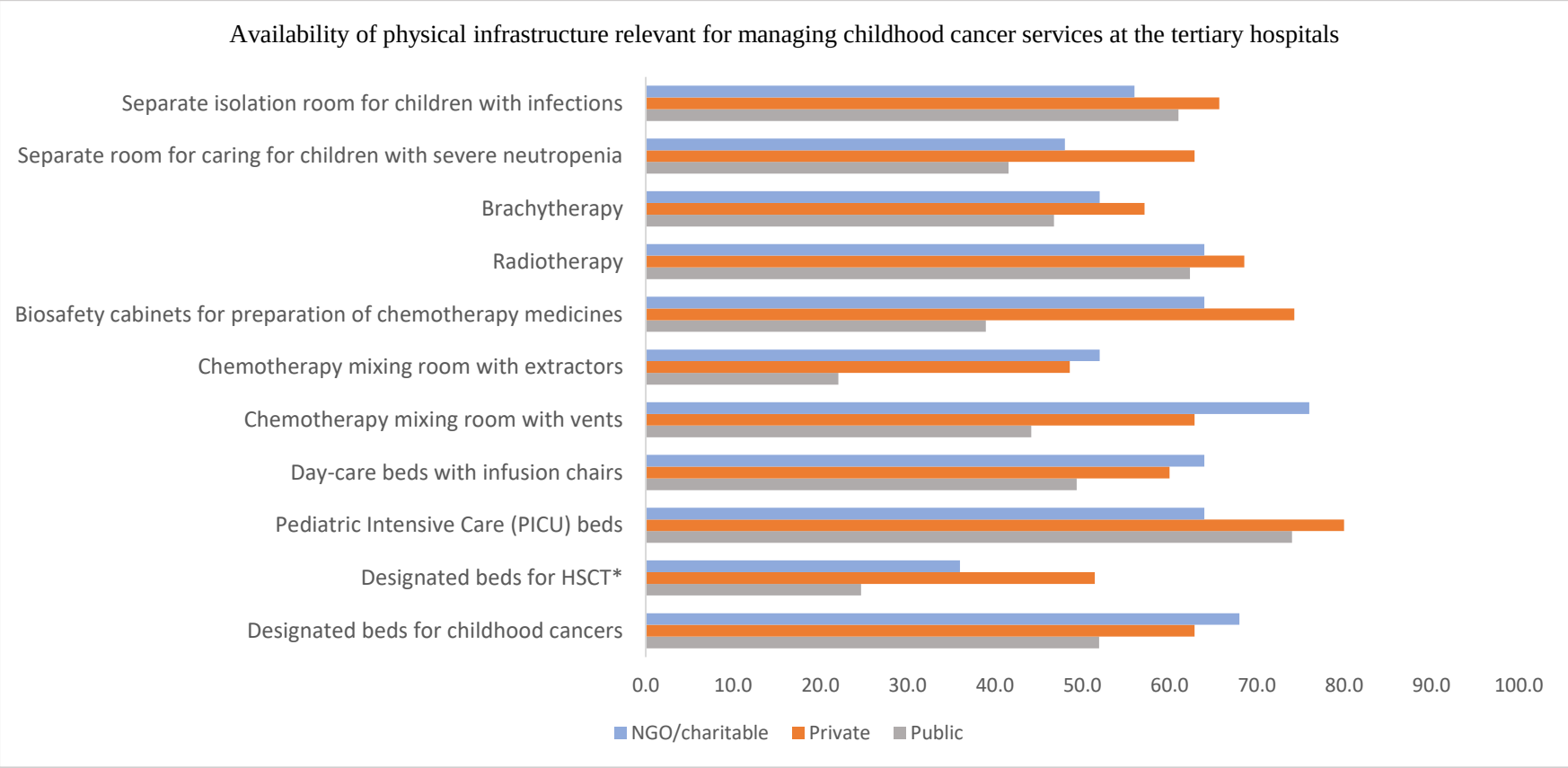

Fig. 18

3.10 Medications for treating childhood cancer

3.10.1 Availability of medications at tertiary hospitals*

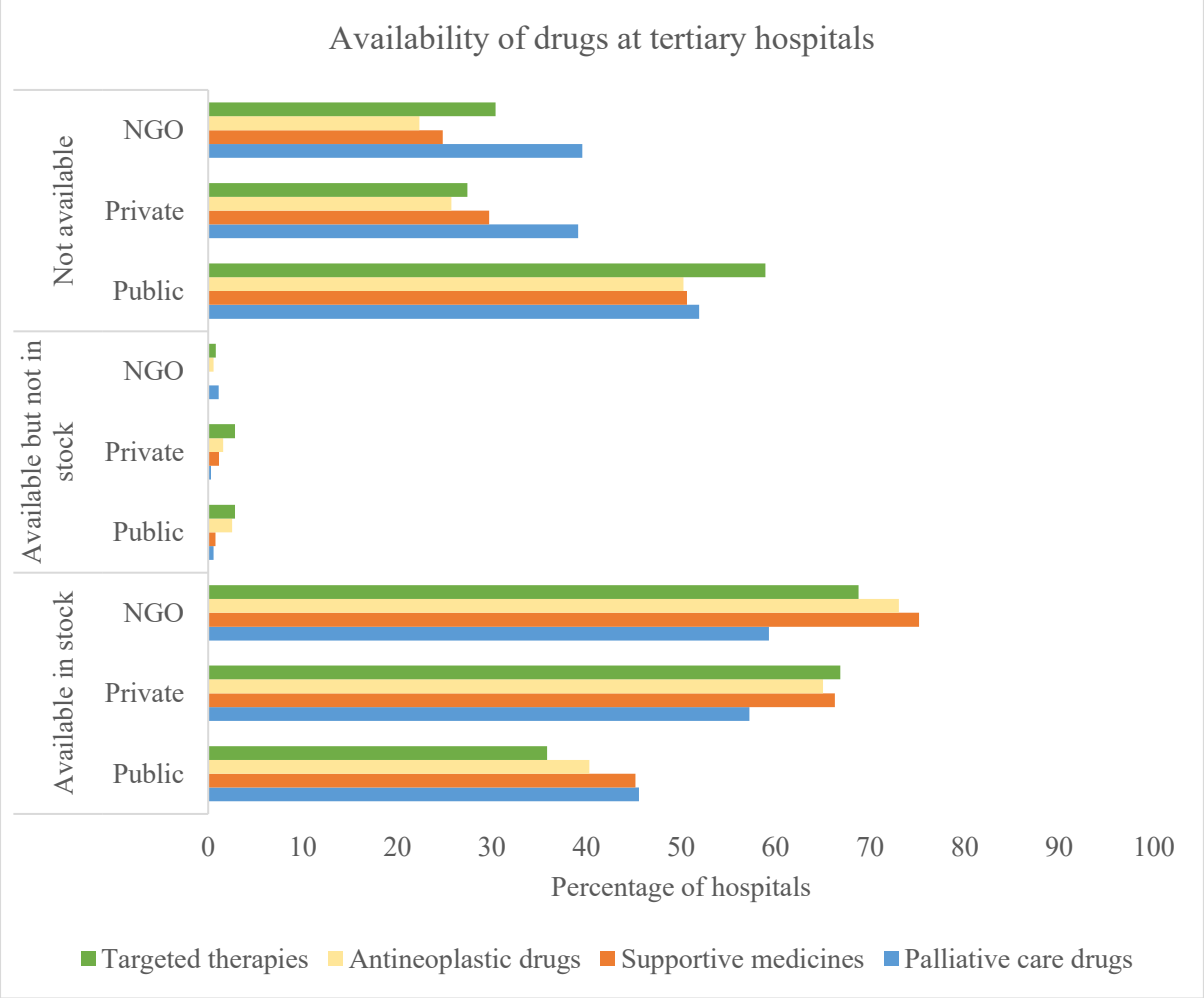

Fig. 19

**Detailed drug-wise figures are shown in the annexures*

3.10.2 Procurement of medications when not available at tertiary hospitals

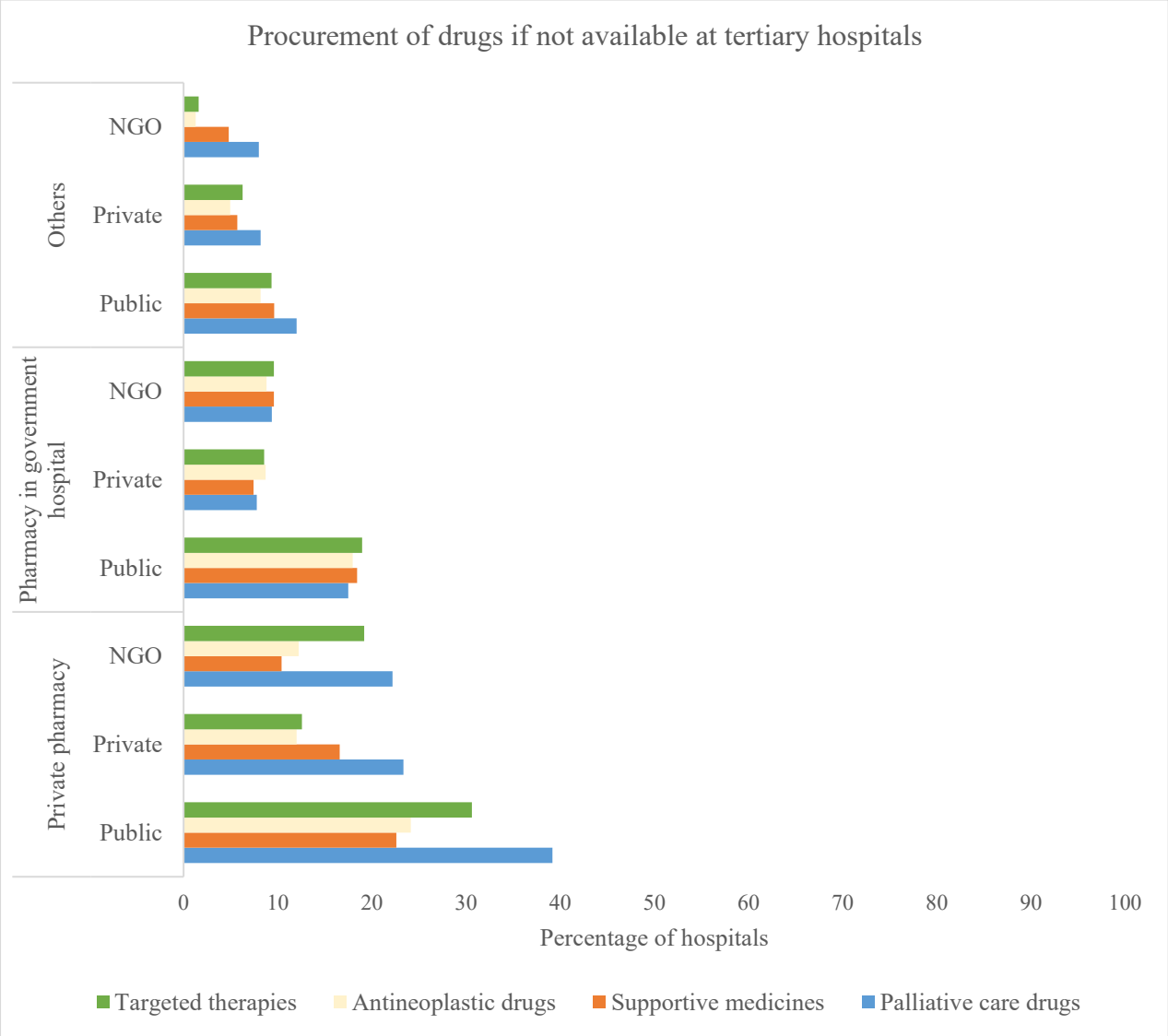

Fig. 20

3.10.3 Cost of medications at tertiary hospitals

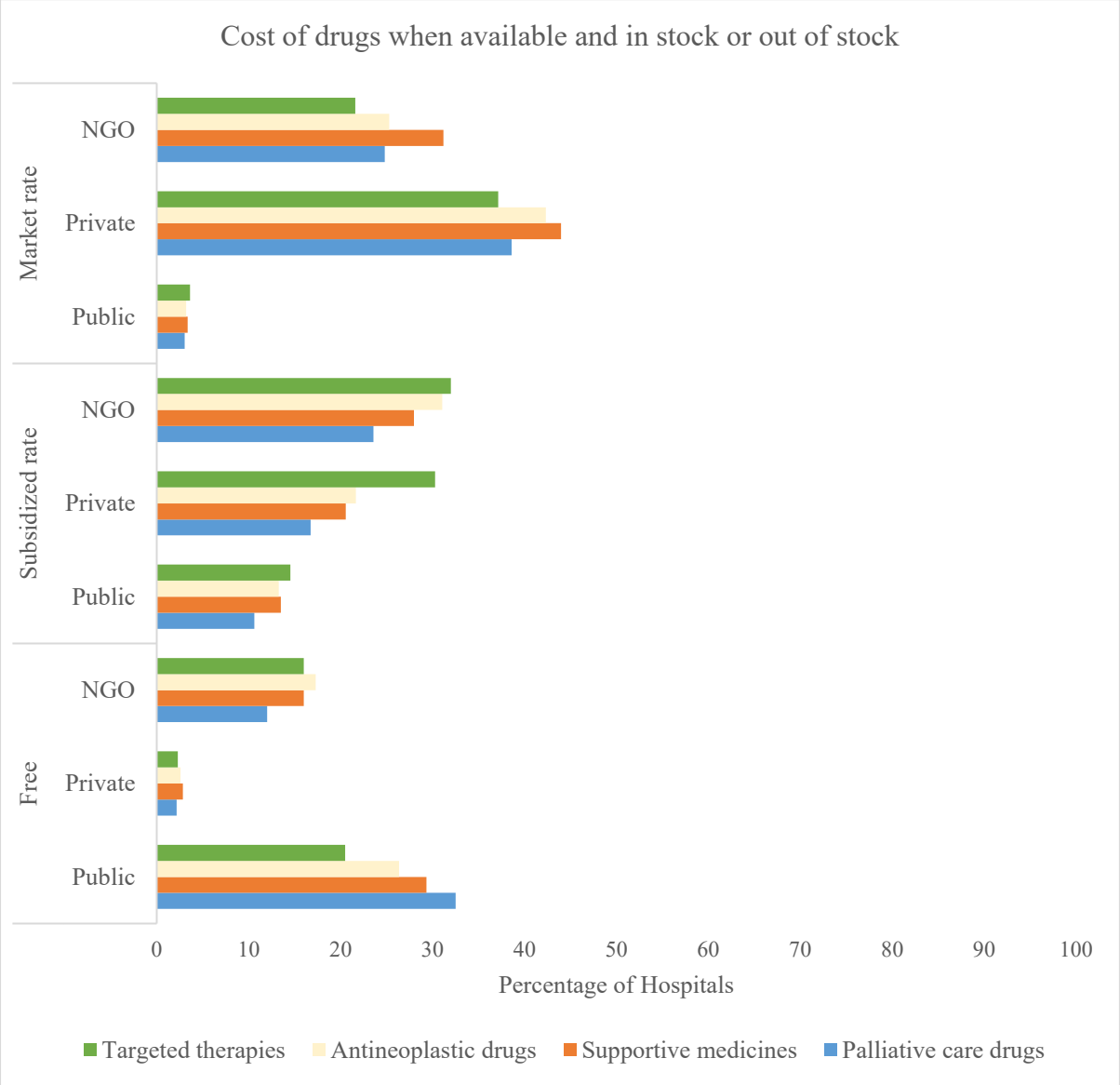

Fig. 21

3.10.4 Availability of cancer-treating drugs at secondary level hospitals

3.10.4.1 Public hospitals

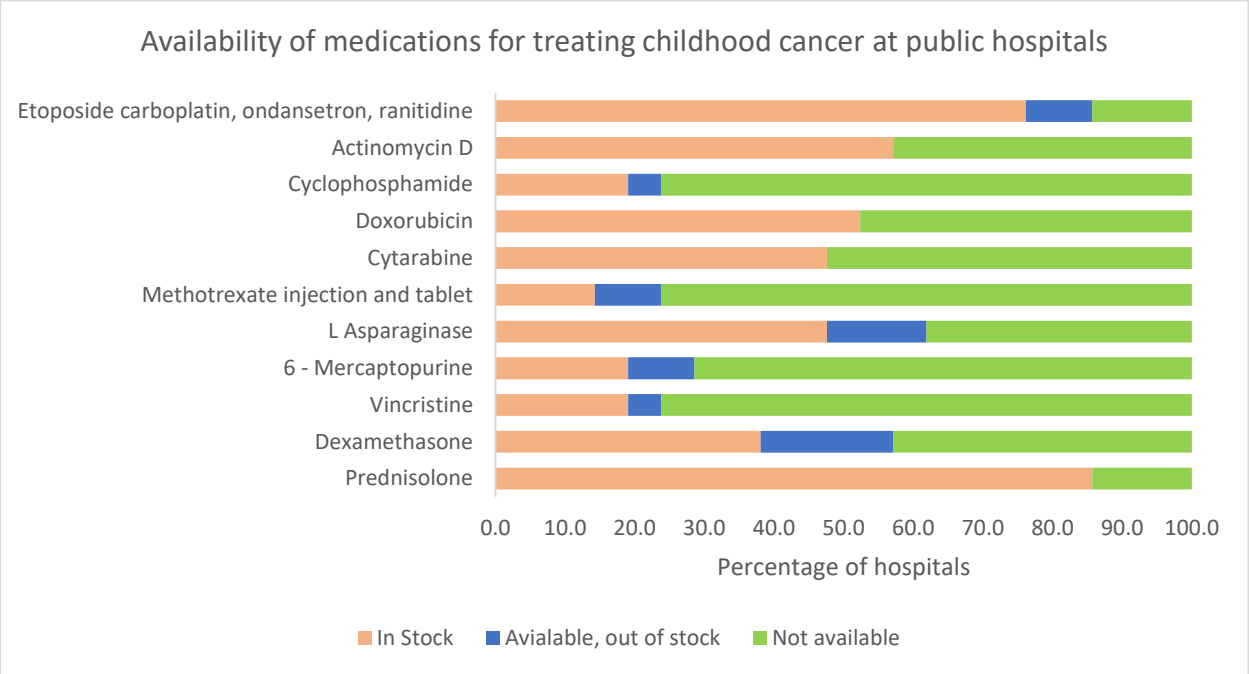

Fig. 22

3.10.4.2 Private hospitals

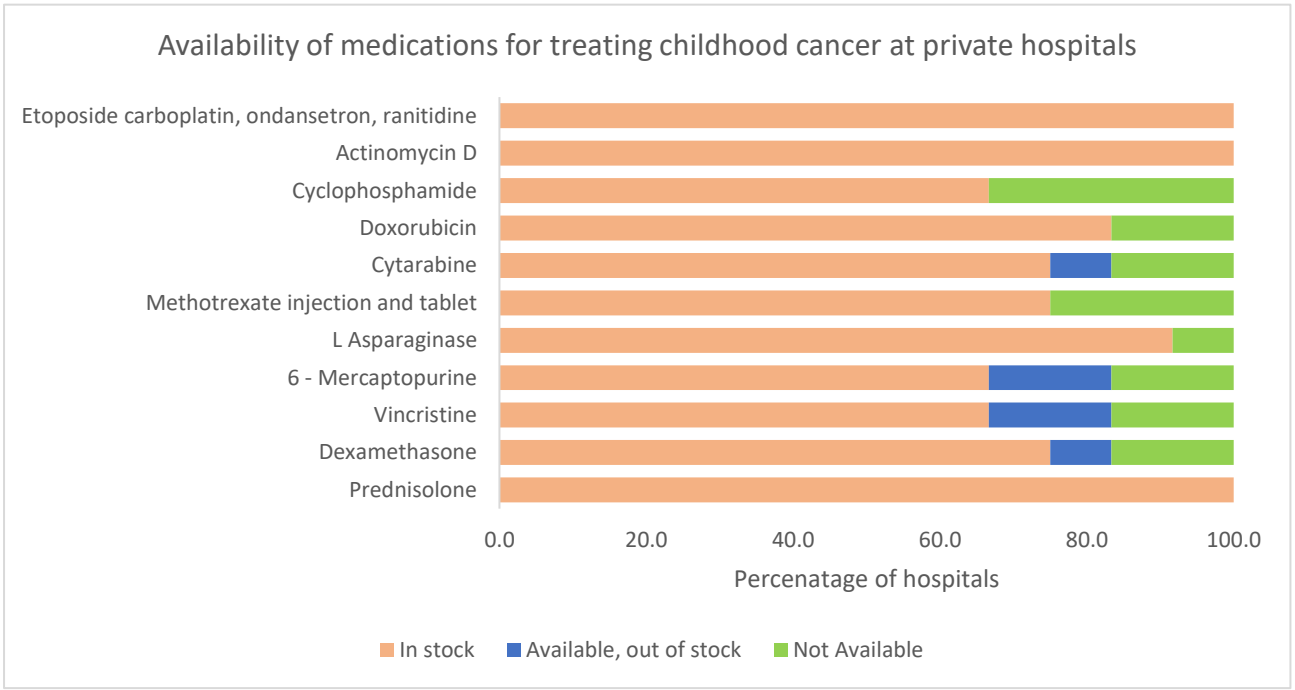

Fig. 23

3.11 Treatment guidelines

Table 9: Percentage of tertiary hospitals using treatment guidelines for the management of specific cancers

Cancer type	Public (n = 52)		Private (n = 23)		NGO/charitable (n = 19)	
	n	%	n	%	n	%
Leukaemia	51	98.07	23	100	19	100
Lymphoma	50	96.15	23	100	19	100
Brain tumours	47	90.38	20	86.95	17	89.47
Neuroblastoma	48	92.30	21	91.30	17	89.47
Wilms tumour	50	96.15	22	95.65	18	94.73
Bone cancer	45	86.53	22	95.65	18	94.73

3.12 Financing of treatment

Table 10

Financing mechanism		Public				Private				NGO/charitable			
		Tertiary (n = 77)	%	Secondary (n = 21)	%	Tertiary (n = 35)	%	Secondary (n = 13)	%	Tertiary (n = 25)	%	Secondary (n = 1)	%
1	Ayushman Bharat Scheme	63	81.8	13	61.9	16	45.7	6	46.2	12	45.7	0	
2	Govt health insurance: CGHS	42	54.5	-	-	11	31.4	-	-	13	31.4	-	-
3	Govt health insurance: ESI	18	23.4	-	-	27	77.1	-	-	15	77.1	-	-
4	Govt health insurance: Any other	3	3.9	-	-	11	31.4	-	-	1	31.4	-	-
5	Any other state-specific scheme	44	57.1	11	52.4	28	80.0	10	76.9	19	80.0	1	100
6	Private insurance	32	41.6	3	14.3	24	68.6	10	76.9	19	68.6	1	100
7	Hospital-based insurance	19	24.7	1	4.8	5	14.3	0		4	14.3	0	-
8	Self-financed	-	-	11	52.4	-	-	10	76.9	-	-	1	100
9	Funding provided by charitable organizations	-	-	10	47.6	-	-	3	23.1	-	-	1	100
10	Any other	-	-	8	38.1	-	-	6	46.2	-	-	1	100

3.13 Pediatric oncology training programmes

Table 11

S. No.	Courses	Availability of training courses at tertiary hospitals							
		Public		Private		NGO/charitable		Total	
		n	%	n	%	n	%	n	%
1	D.M. pediatric oncology	4	5.2	0	0.0	1	4.0	5	3.7
2	FNB in pediatric oncology	4	5.2	3	8.6	2	8.0	9	6.7
3	IAP PHO Fellowship	4	5.2	3	8.6	4	16.0	11	8.1
4	Fellowship in pediatric oncology (Besides FNB and IAP PHO)	3	3.9	2	5.7	4	16.0	9	6.7
5	Diploma in oncologic nursing	6	7.8	3	8.6	3	12.0	12	8.9
6	Certificate course in pediatric oncology for nurses/doctors	4	5.2	2	5.7	2	8.0	8	5.9
7	Any other	4	5.2	4	11.4	4	16.0	12	8.9

3.14 Childhood cancer related activities on awareness and early diagnosis

Table 12

Type of activity	Public				Private				NGO/charitable			
	Tertiary		Secondary		Tertiary		Secondary		Tertiary		Secondary	
N	n	%	n	%	n	%	n	%	n	%	n	%
Availability of IEC (Information, Education and communication) material -pamphlets/posters in waiting areas	40	51.9	10	47.6	21	60.0	6	46.2	13	52.0	1	100
Social media campaign	21	27.3	7	33.3	15	42.9	4	30.8	13	52.0	1	100
Public talks/seminars by experts	42	54.5	6	30.0	23	65.7	6	50.0	14	56.0	1	100
Training of all cadre of health care providers for early diagnosis	29	37.6	7	33.3	18	51.4	3	23.1	11	44.0	1	100
Screening for retinoblastoma in siblings of a patient with retinoblastoma	-	-	5	23.8	-	-	3	23.1	-	-	1	100
Any other	4	5.1	2	11.1	2	5.7	1	8.3	4	16.0	1	100

3.15 Medical record system at tertiary hospitals

Table 13

Medical record system at tertiary hospitals	Public (n = 77)		Private (n = 35)		NGO/charitable (n = 25)	
	n	%	n	%	n	%
Electronic system for patient records in tertiary Hospitals	40	51.9	24	68.5	20	80.0

3.16 Research activities among the tertiary hospitals

Table 14

Research activities among the tertiary hospitals	Public (n = 77)		Private (n = 35)		NGO/charitable (n = 25)	
	n	%	n	%	n	%
Active paediatric oncology clinical research program at Hospital or paediatric oncology unit/ward	19	24.6	9	25.7	8	32.0

Part B. Barriers and facilitators in the delivery of childhood cancer services in India

3.17 Challenges faced in diagnosing and treating childhood cancers

3.17.1 Tertiary level hospitals

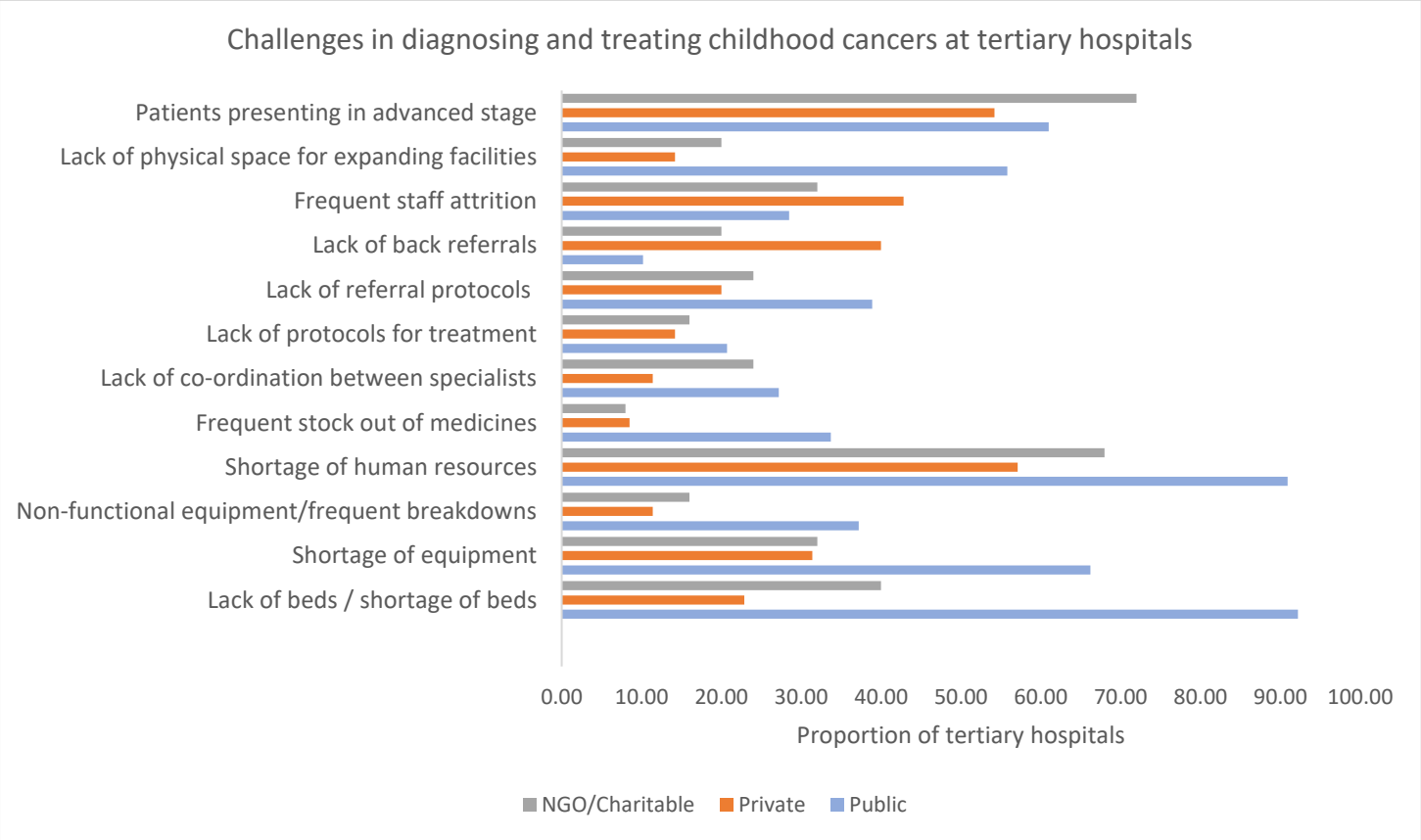

Fig. 24

3.17.2 Secondary level hospitals

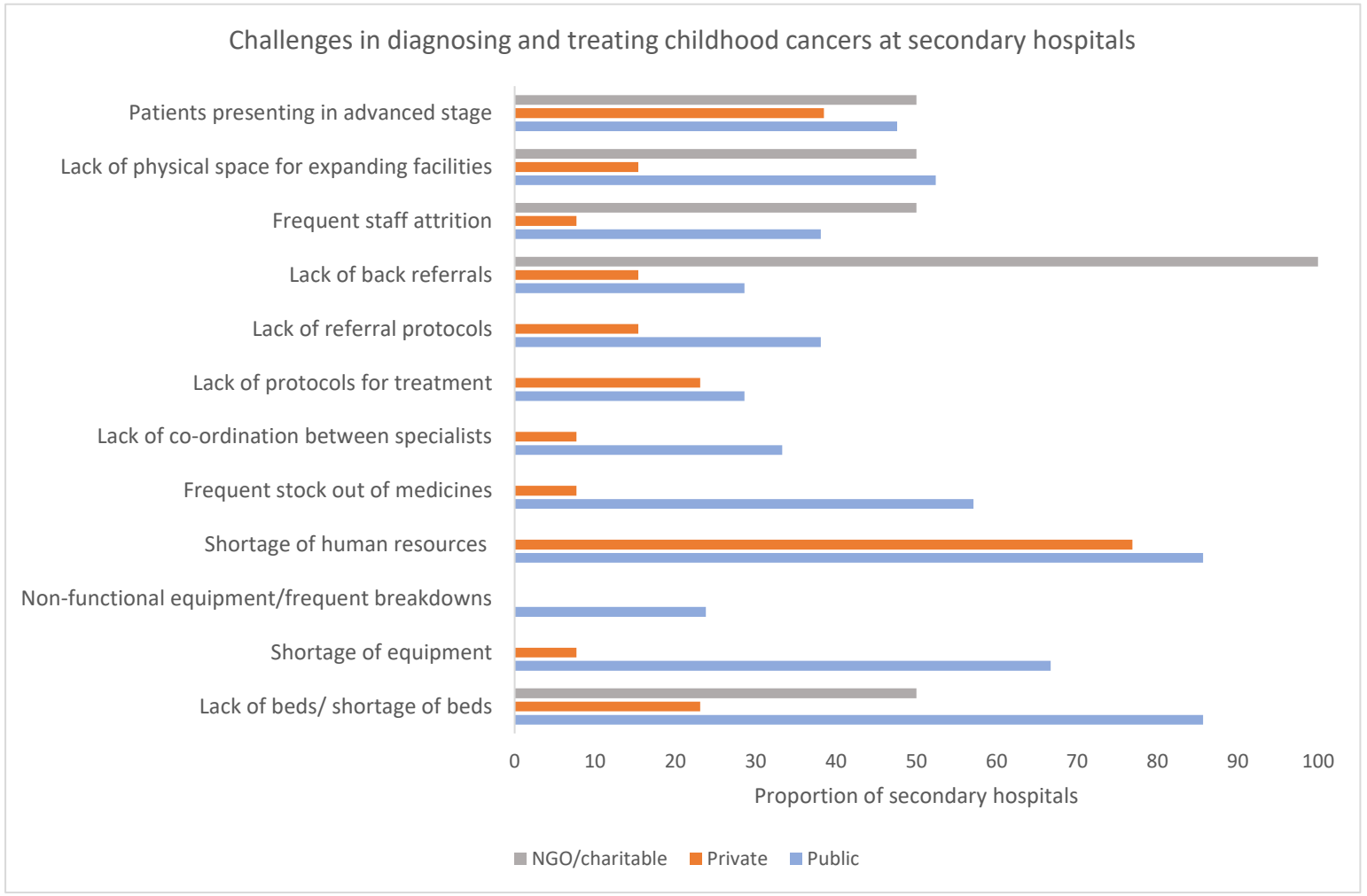

Fig. 25

3.18 Challenges faced by patients and caregivers regarding treatment

3.18.1 Tertiary level hospitals

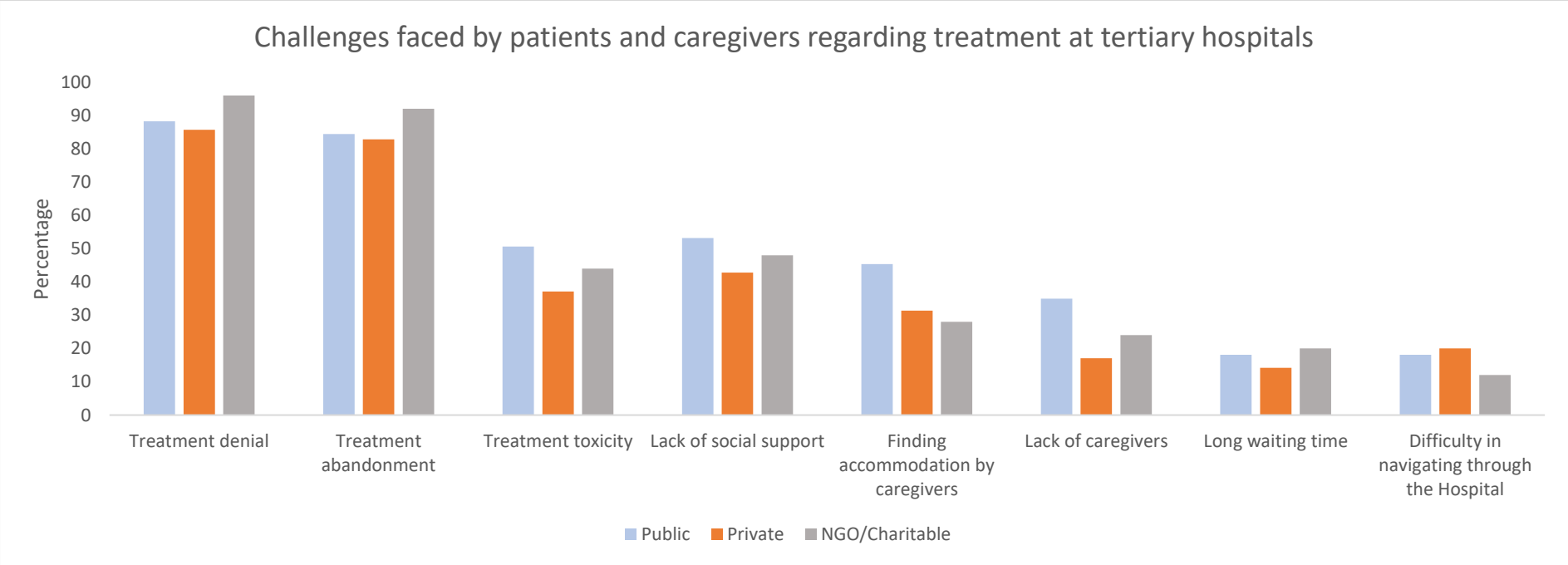

Fig. 26

3.18.2 Secondary level hospitals

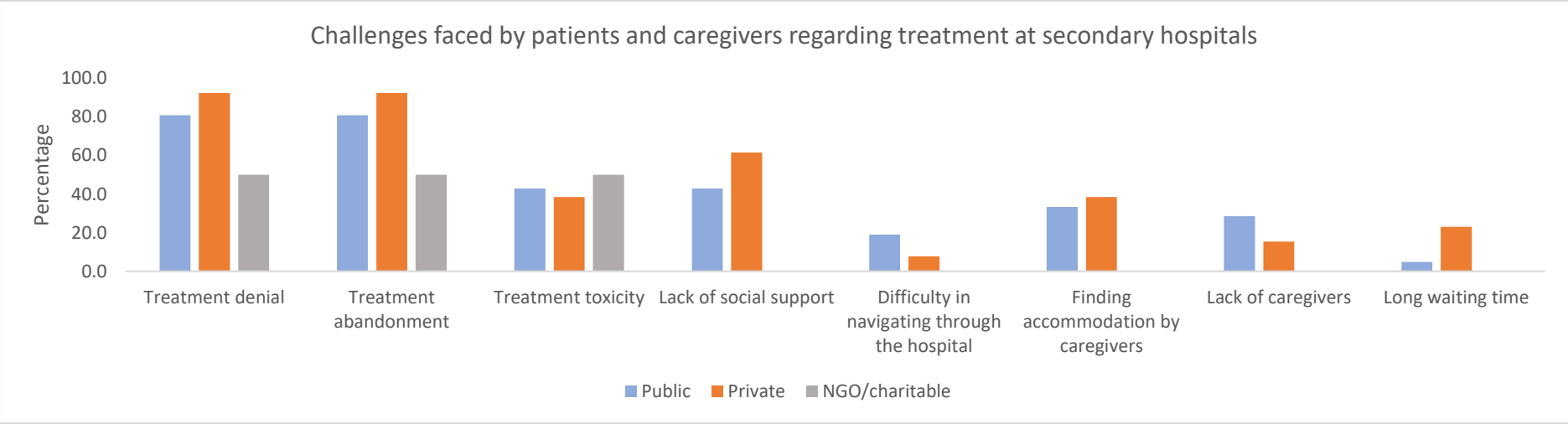

Fig. 27

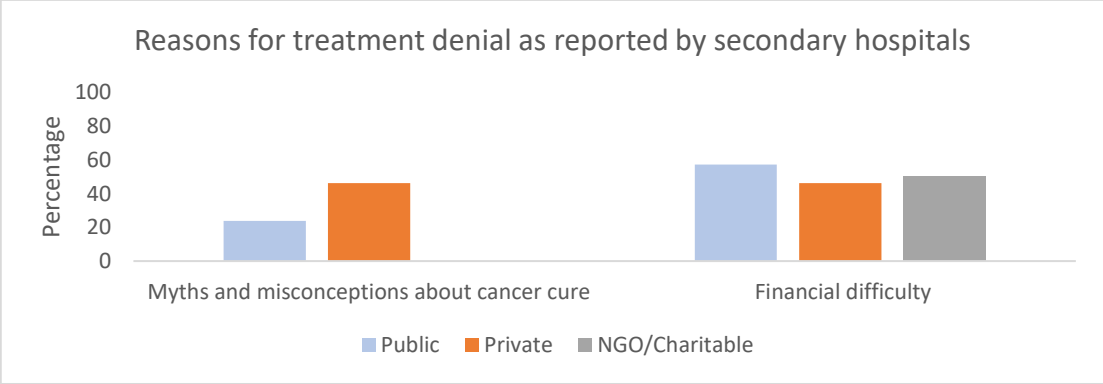

Fig. 28

3.18.3 State nodal officers and civil society organizations/ NGOs'

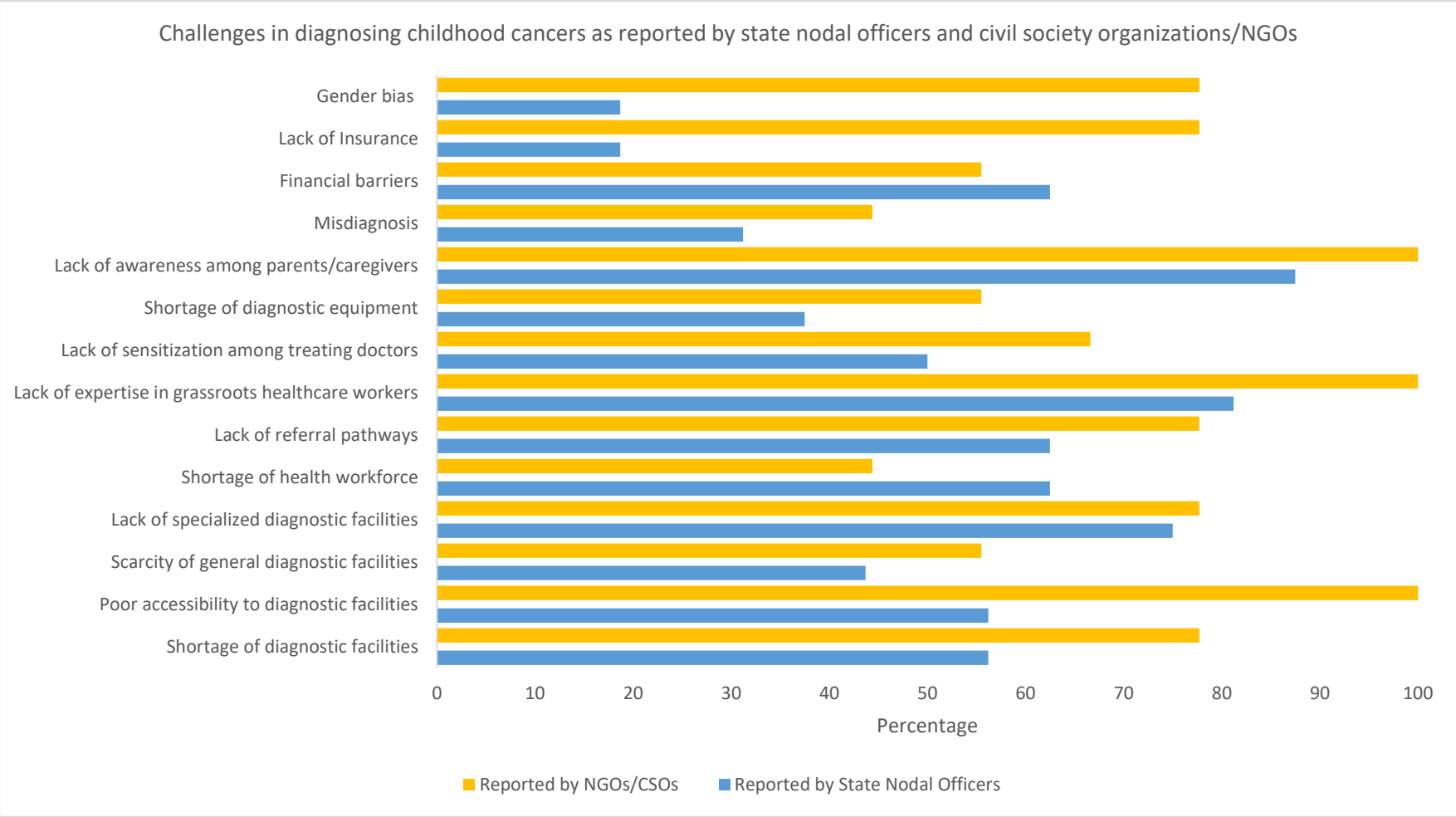

Fig. 29

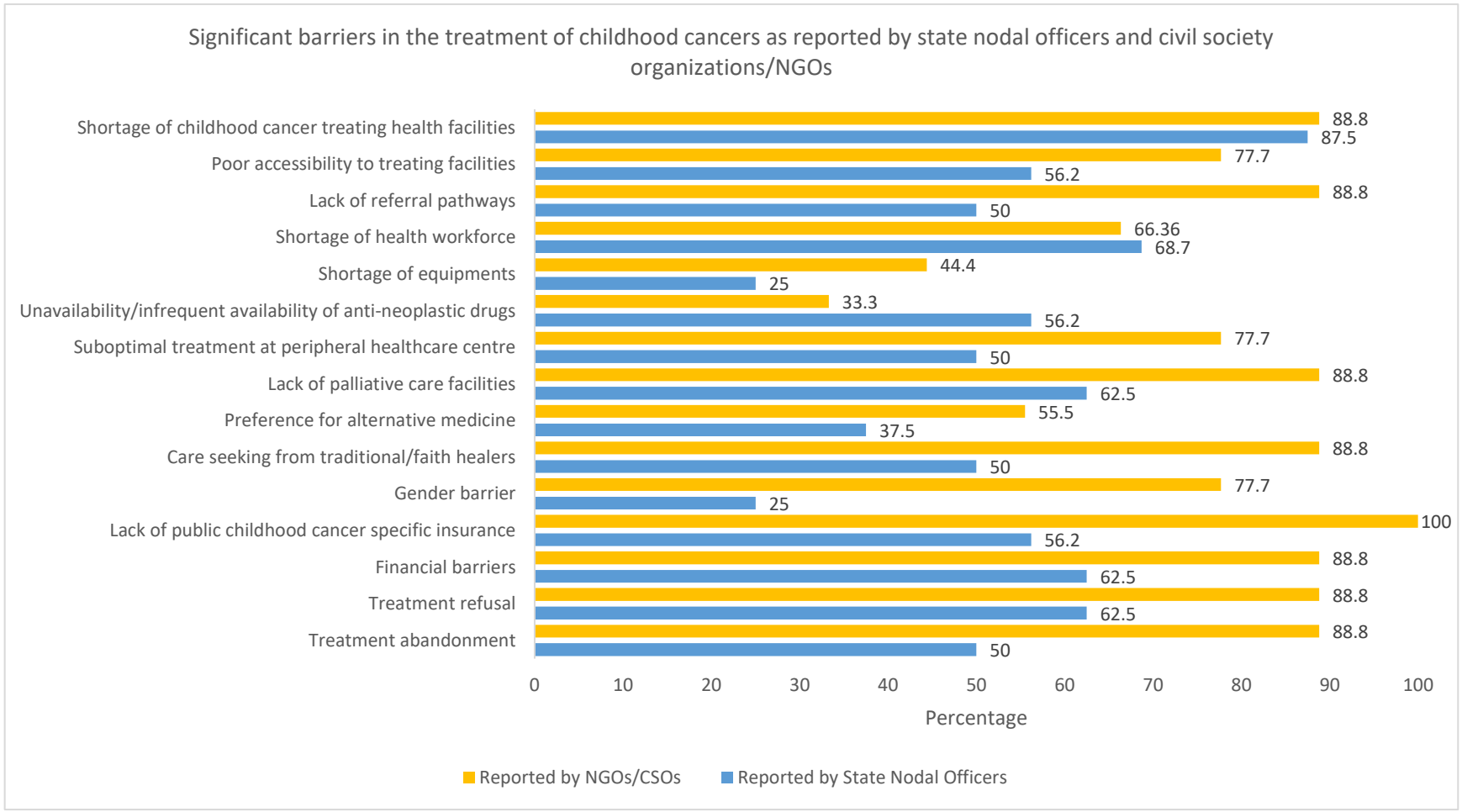
Significant barriers in the treatment of childhood cancers as reported by state nodal officers and civil society organizations/NGOs
Shortage of childhood cancer treating health facilities
Poor accessibility to treating facilities
Lack of referral pathways
Shortage of health workforce
Shortage of equipments
Unavailability/infrequent availability of anti-neoplastic drugs
Suboptimal treatment at peripheral healthcare centre
Lack of palliative care facilities
Preference for alternative medicine
Care seeking from traditional/faith healers
Gender barrier
Lack of public childhood cancer specific insurance
Financial barriers
Treatment refusal
Treatment abandonment
88.8
87.5
77.7
56.2
88.8
50
66.36
68.7
44.4
25
33.3
56.2
77.7
50
88.8
62.5
55.5
37.5
88.8
50
77.7
25
100
56.2
88.8
62.5
88.8
62.5
88.8
50
0
10
20
30
40
50
60
70
80
90
100
Percentage
Reported by NGOs/CSOs
Reported by State Nodal Officers

Fig. 30

3.19 Impact of COVID 19 pandemic on the delivery of childhood cancer care services

3.19.1 Tertiary hospitals

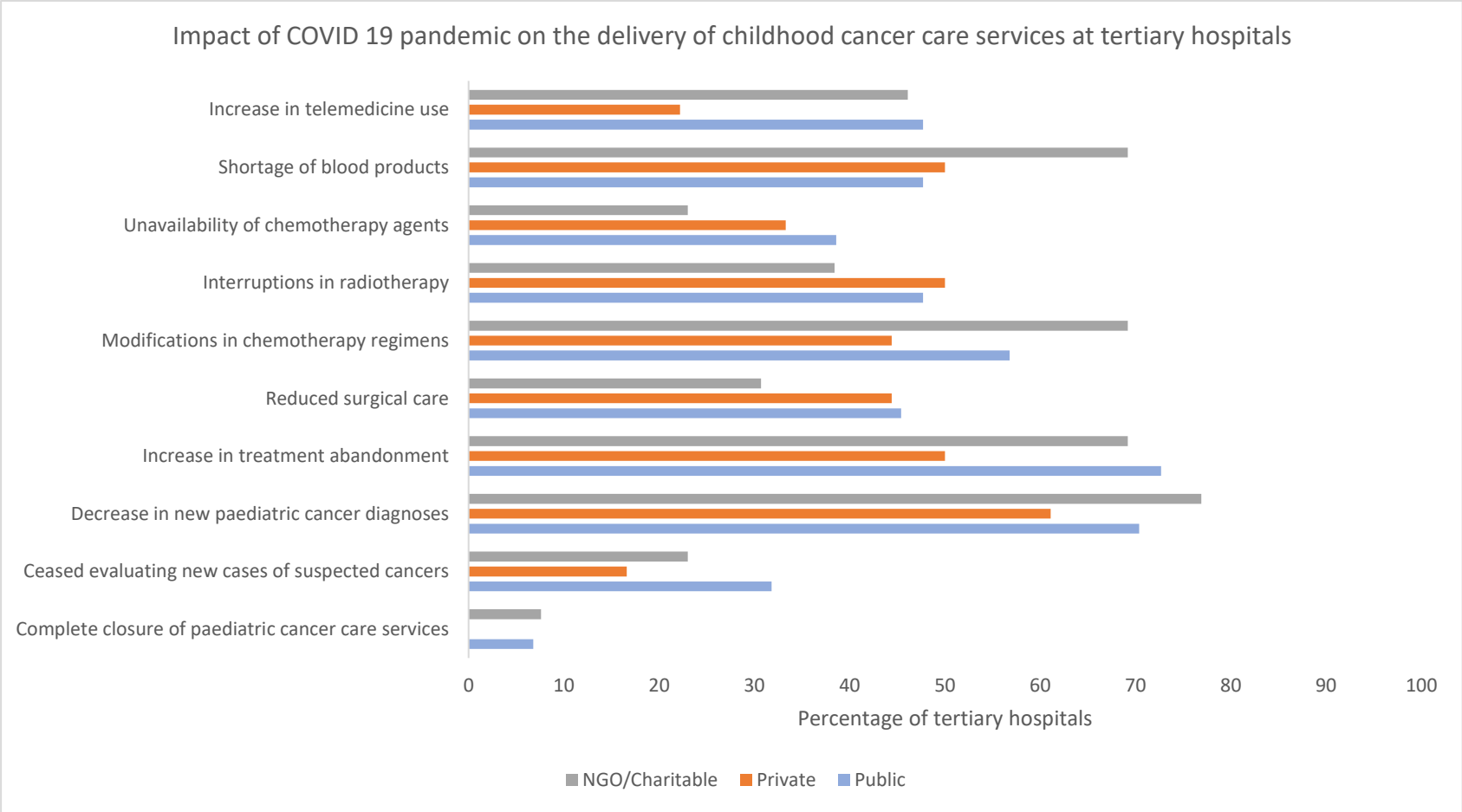

Fig. 31

3.19.2 Secondary level hospitals

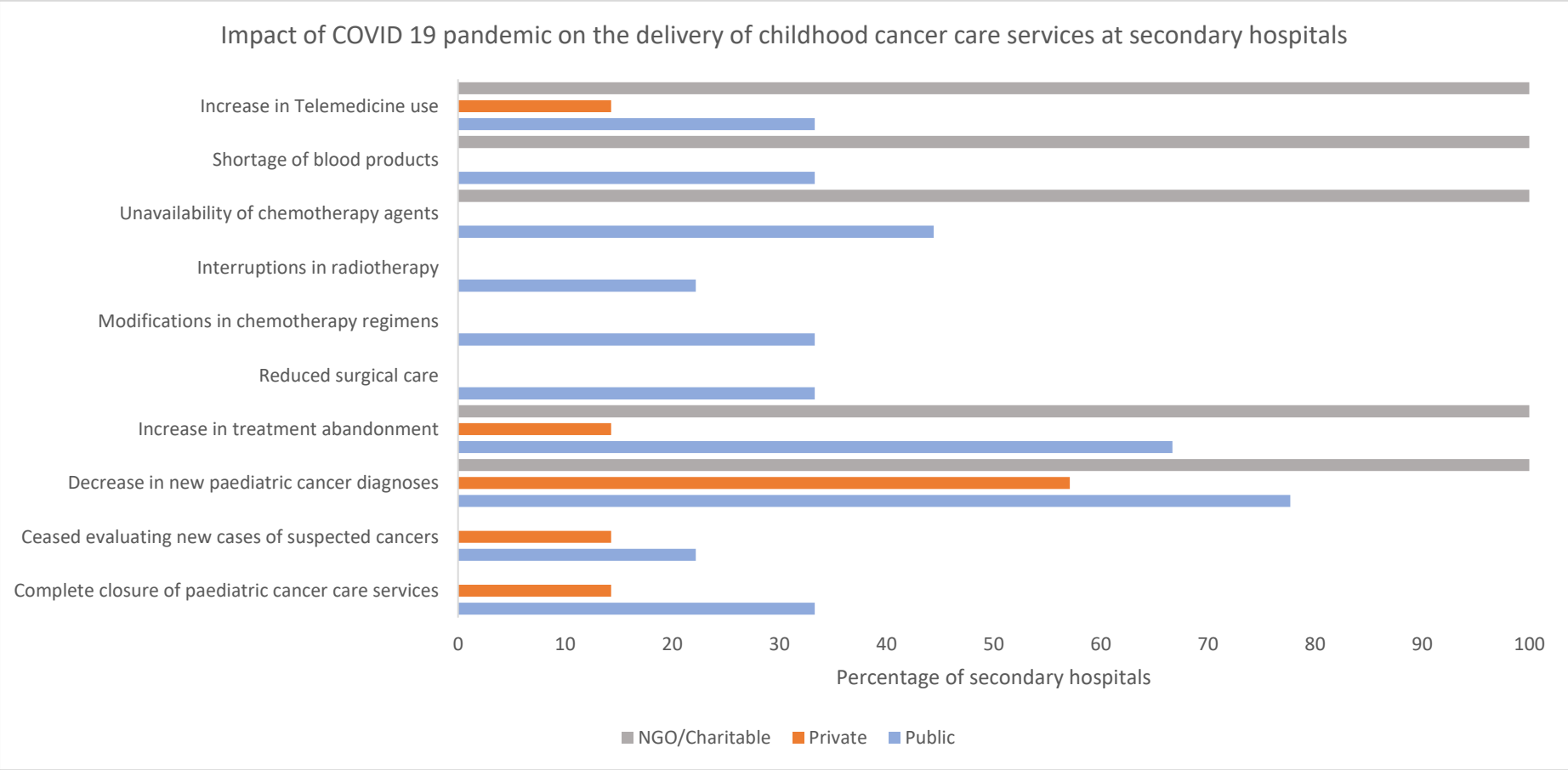

Fig. 32

4. Suggestions on how the following components of childhood cancer care could be improved and strengthened (all stakeholders)

Table 15

S. No.	Suggestion	Tertiary		Secondary		State Nodal Officers		Civil Society Organizations	
		N	%	N	%	N	%	N	%
Referral pathway									
1	Creation of linkage/ referral system, Co-ordination within cancer treating facilities	17	25.8	10	41.7	04	50	02	28.6
2	Awareness and Education among the healthcare professionals	14	21.2	01	4.2	-	-	04	57.1
3	Same day/ Timely referral / Early diagnosis / Establishment of better communication pathways with the cancer-treating centres / well-defined protocols for referral	08	12.1	11	45.8	01	12.5	-	-
4	Digitization/list of availability of various centres that provide childhood cancer care	09	13.6	-	-	-	-	-	-
5	To establish a separate pediatric oncology unit/department with trained staff and infrastructure	05	7.6	-	-	-	-	-	-
6	MoU between cancer treating centres regarding referral	04	6.1	-	-	-	-	-	-
7	Referral to regional cancer care centres	05	7.6	-	-	-	-	-	-
8	Sensitization of PHC/CHC staff	02	3.0	01	4.2	01	12.5	01	14.3
9	Provision of ambulance services/vehicle support	02	3.0	-	-	01	12.5	-	-
10	Better working between health institutions from primary to tertiary level	-	-	01	4.2	-	-	-	-
11	Development and implementation of childhood cancer policy	-	-	-	-	01	12.5	-	-
Diagnosis									
1	Improving and strengthening diagnostic facilities / Availability of diagnostic services near the treating hospital	31	60.8	18	75.0	07	100	03	50.0

S. No.	Suggestion	Tertiary		Secondary		State Nodal Officers		Civil Society Organizations	
		N	%	N	%	N	%	N	%
2	Increasing public awareness regarding childhood cancer symptoms	04	7.8	02	8.3	-	-	02	33.3
3	Training of the paediatricians for early diagnosis of cancer	07	13.7	-	-	-	-	-	-
4	Manpower support for treating childhood cancers / Establishing childhood cancer diagnosis and treatment facilities	04	7.8	02	8.3	-	-	01	16.7
5	Early diagnosis through the availability of paediatrician experts in pediatric oncology/pediatric oncologist, diagnostics equipment's/laboratory and PET scans	02	3.9	01	4.2	-	-	-	-
6	Multidisciplinary/tumour board meetings	01	2.0	01	4.2	-	-	-	-
7	Digital Documentations for multi-speciality opinion	02	3.9	-	-	-	-	-	-
Treatment availability and accessibility									
1	Free cancer treatment and availability of free drugs through Government funds	12	21.1	06	31.6	03	30	-	-
2	Man-power support and infrastructure facilities	14	24.6	01	5.3	04	40	03	60
3	Availability of modern equipment and drugs for cancer care	08	14.0	04	21.1	02	20	01	20
4	Awareness regarding cancer treatment among the general public	08	14.0	01	5.3	-	-	-	-
5	Outreach to cancer clinics in rural areas with trained staff for chemotherapy drugs administration and management	04	7.0	02	10.5	-	-	01	20
6	Training of paediatricians for effective cancer care	05	8.8	03	15.8	01	10	-	-
7	Financial and Social Support	06	10.5	02	10.5	-	-	-	-
Quality of care									
1	Improved infrastructure and manpower	18	34.0	10	50	03	42.9	02	33.3
2	Training of nurses/staff	15	28.3	04	20	-	-	01	16.7

S. No.	Suggestion	Tertiary		Secondary		State Nodal Officers		Civil Society Organizations	
		N	%	N	%	N	%	N	%
3	Awareness among the caregivers	09	17.0	02	10	-	-	-	-
4	Implementation of childhood cancer care policy	-	-	-	-	01	14.3	-	-
5	Multidisciplinary/tumour board meetings	03	5.7	01	5	-	-	-	-
6	Accreditation and quality auditing/protocol-based care	07	13.2	02	10	-	-	02	33.3
7	Financial and Social Support	01	1.9	01	5	-	-	01	16.7
8	Continuum of care at peripheral to tertiary level with diagnostic and treatment facility / Proper monitoring at different levels	-	-	-	-	03	42.9	-	-
Capacity building in childhood cancer care									
1	Trained staff for handling Childhood Cancer Care/regular training of pediatric staff	24	38.7	08	40	06	66.7	-	-
2	Manpower support and infrastructure/more cancer centres to be added	22	35.5	08	40	-	-	01	50
3	Introduce courses related to pediatric oncology	08	12.9	01	5	02	22.2	-	-
4	Awareness and education	05	8.1	01	5	01	11.1	01	50
5	Multidisciplinary team approach	03	4.8	02	10	-	-	-	-

5. Summary

The situational analysis was conducted using a cross-sectional survey design. The participants included 137 tertiary level hospitals, 92 secondary level hospitals, 16 State Nodal Officers/NPCDCS officers, and nine civil society organizations/non-governmental organizations (CSOs/NGOs) in 26 states and four union territories (UT). The key study findings are as follows:

(a) Availability of childhood cancer care services

- Childhood cancer care services were provided at over one-third (39.1%) of the Secondary level hospitals, which was higher for private (56.5%) than public (32.8%) hospitals.
- A dedicated paediatric oncology department was available in less than half of the public and private tertiary hospitals.
- In secondary-level public hospitals, treatment for childhood cancers was mainly provided through the pediatric medicine departments.
- There was a shortage of hospice care services at tertiary hospitals and medical social services at secondary hospitals
- Over three quarters (76.6%) of the public tertiary hospitals adopted a multidisciplinary team approach for childhood cancer treatment, compared to 35% of the private hospitals.
- The most frequently employed mechanism for following up with childhood cancer patients (in between hospital visits) was through telephonic follow-up.

(b) Referral linkages

- Over two-thirds of government tertiary hospitals had referral linkages with lower-tier non-childhood cancer-treating facilities, versus 48.7% of private hospitals
- Written mode of referring patients was the most frequently employed patient referral mechanism
- Less than a tenth of the government tertiary hospitals and a little over one-third of the private hospitals had formal agreements for a referral.
- 74.4% of public and 60% of private secondary level hospitals had referral linkages with tertiary cancer treating hospitals.
- Referral linkages with primary health facilities were present for 60.9% of the public and 52.1% of private secondary-level health facilities.

(c) Availability of diagnostic services

- Over 90% of the tertiary hospitals had facilities for histopathology; however, a lower proportion of public tertiary hospitals had facilities for immunohistochemistry, flowcytometric immunophenotyping, cytogenetics, and tumour markers and fluorescence in situ hybridization (FISH).
- Availability of bone and PET scans was lower, especially in public tertiary hospitals.
- Among secondary level hospitals, a higher proportion of private hospitals reported the availability of laboratory and radiologic investigations.

(d) Availability of cancer treatment procedures

- Less than a quarter (20.7%) of the public tertiary hospitals had facilities for Haemopoietic Stem Cell Transplantation (HSCT) compared to half of the private tertiary hospitals (54.2%)
- The proportion of public sector hospitals that provided bone marrow biopsy, drug infusion chemotherapy, intrathecal chemotherapy, immunotherapy and brachytherapy was less than two-thirds of the hospitals
- The proportion of hospitals providing focal therapy was deficient, public (20.7%) and private (31.4%).
- The majority of the hospitals had treatment protocols for the management of chemotherapy, febrile neutropenia and central venous access devices.

(e) Availability of human resources

- At public tertiary hospitals, less than half of the hospitals had a pediatric oncologist (48%), pediatric oncosurgeon (14.2%), pediatric intensivist (38.9%), and medical oncologist (49.3%), and palliative care physician (37.6%).
- About a quarter of the public tertiary hospitals not having regular oncology specialists made arrangements for specialized consultations
- Nurses trained in pediatric cancer and palliative care were available in less than 50% of the public and private tertiary hospitals.
- Dieticians were available in 52.4% of the secondary hospitals, while 42.9% of these hospitals had a social worker.

(f) Physical infrastructure, availability of medications and financing of treatment

- A separate neutropenic room, brachytherapy treatment planning room, biosafety units for chemotherapeutic drugs, separate chemotherapy mixing room and daycare beds were available in less than half of the public sector tertiary hospitals
- A higher proportion of private hospitals had the relevant physical infrastructure relevant for managing childhood cancer care services
- Less than 50% of the public tertiary hospitals had stocks of all four classes of cancer-treating drugs. The availability of targeted therapies was the lowest.
- The proportion of private and NGO tertiary hospitals having available stocks of cancer-treating drugs was higher than public sector hospitals
- Private pharmacies constituted the major source of procuring drugs in case of non-availability.
- Less than 40% of the public sector tertiary hospitals provided all classes of cancer-treating drugs.
- Drugs including Cyclophosphamide, Methotrexate, Mercaptopurine and Vincristine were available in less than a third of the public tertiary level hospitals.
- The most commonly adopted financing mechanism comprised the Ayushman Bharat Scheme at public tertiary and secondary level public hospitals and ESI/State specific schemes at private tertiary hospitals.

(g) Training programmes, research, record maintenance and IEC activities

- The proportion of hospitals offering degree and training programmes in pediatric oncology for medics and paramedics was less than 10%
- A higher proportion of private facilities provided such kinds of training programmes
- Over half of the tertiary level hospitals had IEC (information, education and communication) material -pamphlets/posters on childhood cancer in waiting areas and organized public talks/seminars by experts.
- The health care providers in less than one-third of the public and private secondary hospitals had received training for early diagnosis of childhood cancer
- None of the tertiary level hospitals conducted retinoblastoma screenings in siblings of retinoblastoma patients. At the same time, this was done in less than a quarter of the public and private secondary level hospitals.
- A lower proportion of public tertiary level hospitals maintained electronic health records than private and NGO/charitable hospitals.
- About one-fourth of the tertiary hospitals had active pediatric oncology clinical research programs at hospital or pediatric oncology unit/ward

(h) Challenges faced in the diagnosis and treatment of childhood cancers

- Public tertiary and secondary level hospitals faced challenges with a shortage of human resources, lack of beds, shortage of equipment and lack of physical space for extending facilities
- Treatment denial and treatment abandonment were the commonest challenges faced in the treatment of childhood cancers
- According to the state nodal officers and civil society organizations, The main challenges in the diagnosis of childhood cancers include gender bias in seeking care, lack of insurance, lack of awareness among parents and caregivers regarding early signs and symptoms, lack of expertise among grass-root level workers in diagnosis and poor accessibility to diagnostic centres due to geographical conditions.
- The main barriers in the treatment of childhood cancers were treatment abandonment, treatment refusal, financial barriers and gender barriers in seeking care, care-seeking from traditional healers, lack of palliative care facilities, sub-optimal treatment at peripheral health centres, poor accessibility, shortage of health workforce and cancer treatment facilities and lack of referral pathways.

(i) Impact of COVID 19 on the delivery of childhood cancer care services

- Childhood cancer care services had been impacted in the majority of the tertiary and secondary hospitals
- The most frequently encountered impact was decreased new diagnoses and increased treatment abandonment rates.

6. The way forward

Most childhood cancers are associated with non-modifiable risk factors. The key to a better prognosis and favourable outcomes is early and accurate diagnosis and timely initiation of effective treatment. The situational analysis of childhood cancer care services in India reiterates a concentration on the availability of childhood cancer care services at the tertiary level of health care.

Childhood cancer policy

Based on the findings from the situational analysis, formulating a childhood cancer policy is essential to ensure the availability of exclusive pediatric oncology services and infrastructure to suit the unique needs of childhood cancer patients, such as supportive care and treatment adherence and address the barriers to diagnosis and treatment. Integration of childhood cancer as a part of the national cancer control response should be taken up as a matter of priority.

This calls for pro-active and collated efforts from all concerned stakeholders, including governing authorities, policymakers, health care providers, civil society organisations, families of the patient, patient groups and laypersons.

Early diagnosis

Intensive awareness is needed to sensitise health care providers and the community about childhood cancer symptoms and signs through concerted efforts between programme officers, providers, and the community. General physicians and primary care providers must be trained to identify signs and symptoms in children with cancer, enabling timely referral. IEC campaigns, integration of early diagnosis of childhood cancers with existing national health programmes such as Rashtriya Bal Swasthya Karyakram (RBSK), the reproductive and child health programme (RCH), NPCDCS and school health programmes could be explored for the integration and provision of such services. The WHO module on early diagnosis of childhood cancer uses the integrated management of childhood illness (IMCI) strategy to examine the presence of pediatric cancer and could be considered for integration into the currently implemented systems.

Besides histopathology, accelerating the availability of diagnostic biomarkers should be strengthened in public sector hospitals through intensive capacity building by institutions of excellence.

Developing applications that use machine learning algorithms for the early diagnosis of childhood cancers such as retinoblastoma can complement the efforts of a physician and thereby reduce the workload. Such deep learning tools for prediction and early diagnosis make implementation at primary health care levels feasible.

Strengthening pediatric oncology services and referral pathways

While setting up a specialised unit may not be feasible in every hospital, providing these services through existing infrastructure with the necessary facilities for diagnosis and treatment may be best. In the present survey, less than half of the tertiary hospitals had an entire pediatric oncology unit. Pediatric oncology service could be expanded by strengthening referral and back referral linkages between a tertiary nodal hospital and secondary health facilities. This could also be achieved through a robust end-to-end technological connectivity between the nodal cancer hospital and district hospital that can provide telemedicine services to enable early diagnosis and initiation of treatment. Oncology residents could be posted at district hospitals on a rotatory basis to overcome shortages in the health workforce. Secondary level health facilities could be upgraded into satellite facilities equipped with basic infrastructure with systemic therapy units. This would reduce travel time, ensure a continuum of care and be cost-effective.

Public-private partnerships would be very beneficial for addressing gaps in the availability of human resources, diagnostic and treatment services and supportive care. Medical social care workers' vital role in counselling and support to minimise treatment denial and adherence should be considered. Likewise, collaboration with CSOs could be explored to help maintain patient follow-up and treatment adherence.

Financing childhood cancer treatment is an essential matter of concern and requires concerted efforts to scale up the availability. The financial burden of treatment is compounded by out-of-pocket spending on accommodation and daily living expenses when the necessary treatment is available at a distant place. Besides successful treatment, a childhood cancer survivor also needs long-term rehabilitation and supportive care. Under the PM-JAY scheme, pediatric cancer treatment modalities have been included in broad oncologic specialities. A costing exercise of pediatric cancer care services would help develop specific childhood cancer treatment packages.

Palliative care and hospice services should be considered equal to cancer treatment. As described in the preceding sections, these required services could be sought through linkages with private and NGO health facilities.

Pediatric oncology training and research

Formal courses in Pediatric oncology for physicians and nurses need continuing and robust support for expansion and scaling up since these are available at limited centres. There is also a need for Paediatric oncology training programmes for primary care physicians, nurses, grass-root health workers, medical social workers and members of community-based organisations at periodic intervals.

Paediatricians should be encouraged to engage in research in paediatric oncology as they will best be able to identify the unmet clinical needs and gaps and work collaboratively as knowledge brokers with researchers from other fields. Forming a national pediatric oncology research group would be a significant step. The formation of a national childhood cancer registry would help promote pediatric oncology research. An electronic health record system would facilitate ease of case abstraction and data authenticity for running a successful childhood cancer registry. Pediatric cancer outcomes could be significantly improved by adopting evidence-based treatment guidelines and enrolling patients in multicentric clinical trials to evaluate optimal treatment interventions.

Pediatric cancers have a unique profile and health system needs than adult cancers. A multidisciplinary team effort involving coordinated efforts from all concerned players is needed to strengthen and scale up India's availability, accessibility, and quality of childhood cancer care services.

Annexure 1 – List of ICMR investigators and experts

ICMR-NCDIR Investigators

Dr Prashant Mathur Director, ICMR-NCDIR
Dr Anita Nath Scientist E, ICMR-NCDIR
Mr Sudarshan K L Scientist D, ICMR-NCDIR
Dr T.M. Chandra Bhavani Consultant (Medical), ICMR-NCDIR
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Mr Solomon T Project Assistant, ICMR-NCDIR

Expert panel members

Dr Bishnu Rath Giri, WHO
Dr Gampo Dorji, WHO
Dr Pradeep Joshi, WHO
Dr Sanjiv Kumar Dixit Ex-Director, National Health Systems Resource Centre (NHSRC), New Delhi
Dr Rachna Seth Professor of Pediatric Oncology, AIIMS, New Delhi
Dr Ramandeep Arora Senior Consultant, Pediatric Oncology, Max Hospital, New Delhi
Dr Girish Chinnaswamy Head of the Department of Pediatric Oncology TMH, Mumbai

Annexure 2- List of nodal hospitals

State	Nodal Hospital	Nodal officer/s
Andhra Pradesh	Andhra Medical College, Visakhapatnam	Dr V. Surya Rao, Assistant Professor, Department of Community Medicine
Arunachal Pradesh	Tomo Riba Institute of Health and Medical Sciences, Naharlagun	Dr Sopai Tawsik, Senior Pathologist, Department of Pathology
Assam	Dr B. Borooah Cancer Institute, Guwahati	Dr Munlima Hazarika, Professor and In-charge, Department of Medical and Paediatric Oncology
Bihar	All India Institute of Medical Sciences, Patna	1. Dr Lokesh Tiwari, Head of the Department of Pediatrics 2. Dr Chandra Mohan Kumar, Additional Professor, Department of Pediatrics 3. Dr Pritanjali Singh, Additional Professor, Department of Radiotherapy
Chandigarh	Government Medical College & Hospital -32, Chandigarh	Dr Awadhesh Kumar Pandey, Professor and Head of the Department of Radiation Oncology
Chhattisgarh	All India Institute of Medical Sciences, Raipur	Dr Sunil Natha Jondhale, Associate Professor, Department of Paediatric
Gujarat	The Gujarat Cancer & Research Institute, Ahmedabad	Dr Shashank Pandya, Director, Department of Surgical Oncology Dr Anand Shah, Assistant Professor, Department of Community Oncology and Medical Records
Haryana	BPS Government Medical College for Women, Haryana	Dr Manoj Rawal, Associate Professor and Head of the Department of Paediatrics
Jammu and Kashmir	Sher-I-Kashmir Institute of Medical Sciences, Srinagar	Dr Arshad Manzoor Najmi Associate Professor, Department of Radiation Oncology
Jharkhand	Rajendra Institute of Medical Sciences, Ranchi	Dr S. B. Singh, Associate Professor and Statistician, Department of Preventive and Social Medicine
Karnataka	Kidwai Memorial Institute of Oncology, Bengaluru	Dr Avinash T Senior Medical Officer, Department of Paediatric Oncology Dr C Ramesh, Professor & Head, Dept. of Epidemiology & Biostatistics Dr Arun Kumar, Assistant Surgeon, Associate Professor, I/C HOD Dr Vijay CR, Assistant Professor, Dept. of Epidemiology & Biostatistics

State	Nodal Hospital	Nodal officer/s
Kerala	Regional Cancer Centre, Thiruvananthapuram	Dr Priya Kumari T, Professor and Head of the Department of Paediatric Oncology
Madhya Pradesh	All India Institute of Medical Sciences, Bhopal	Prof Shikha Malik, Professor and Head of the Department of Pediatrics Dr Narendra Kumar Chaudhary MD, IAP Fellowship and FNB (pediatric haematology-oncology) Associate Professor Department of Pediatrics
Maharashtra	Tata Memorial Hospital, Mumbai	Dr Atul Budukh Professor of Epidemiology
Manipur	Regional Institute of Medical Sciences, Imphal	Dr Ratan Konjengbam Associate Professor, Department of Pathology
Meghalaya	North Eastern Indira Gandhi National Institute of Health and Medical Sciences (NEIGRIHMS), Shillong	Dr Caleb Harris Associate Professor, Department of Surgical Oncology
Mizoram	Mizoram State Cancer Institute, Aizawl	Dr Jeremy L Pautu, Head of the Department of Medical Oncology
Nagaland	Naga Hospital Authority, Kohima	Dr Vinotsole Khamo, Head of the Department of Pathology & Healthcare Laboratory & Research Centre
New Delhi	Lady Hardinge Medical College and assoc Kalawati Saran Children's Hospital, New Delhi	Dr Varinder Singh, Director-Professor, Department of Pediatrics
Odisha	All India Institute of Medical Sciences, Bhubaneswar	Dr Saroj Kumar Das Majumdar, Additional Professor, Department of Radiotherapy
Puducherry	Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER)	Dr Gunaseelan K, Professor and Head of the Department of Radiation Oncology
Punjab	Government Medical College, Patiala	1. Dr Vijay Kumar Bodal, Professor of Pathology 2. Dr Raja Paramjeet Singh Banipal Professor and Head of the Department of Radiation Oncology
Rajasthan	All India Institute of Medical Sciences, Jodhpur	Dr Puneet Pareek, Additional Professor and Head of the Department of Radiation Oncology

State	Nodal Hospital	Nodal officer/s
Sikkim	Sir Thutob Namgyal Memorial Referral Hospital, Gangtok	Dr Tseten W Bhutia Chief Consultant and Head of the Department of Pathology
Tamil Nadu	Cancer Institute (W.I.A), Chennai	1. Dr R Swaminathan, Professor and Head of the Department of Epidemiology, Biostatistics and Cancer Registry Associate Director, Cancer Institute (WIA) 2. Dr Ventraman Radhakrishnan, Professor, Department of Medical Oncology
Telangana	Nizams Institute of Medical Sciences, Hyderabad	Dr Sadashivudu Gundeti, Additional Professor and Head of the Department of Medical Oncology
Tripura	Regional Cancer Centre, Agartala	Dr Gautam Majumdar MD , Medical Superintendent and Head of Office, RCC Agartala Dr Deep Shikha Das, MD Radiation Oncology
Uttar Pradesh	Super Speciality Paediatric Hospital & Post Graduate Teaching Institute, Noida	Dr Nita Radhakrishnan, Associate Professor and Head of the Department of Pediatric Hematology-Oncology
Uttarakhand	All India Institute of Medical Sciences, Rishikesh	Dr Deepak Sundriyal, Assistant Professor, Department of Medical Oncology-Haematology
West Bengal	Chittaranjan National Cancer Institute, Kolkata	Dr Syamsundar Mandal Head of the Department of Epidemiology and Biostatistics

Annexure 3 - List of participating hospitals

State	Participating Hospitals	Staff
Andhra Pradesh	**Tertiary**	
	King George Hospital, Andhra Medical College, Visakhapatnam	Dr Swamy Naidu Professor and Head of the Department of Paediatrics
	Visakha Institute of Medical Sciences, Visakhapatnam	Dr Satya Prasad Professor of Medicine
	Government Medical College, Srikakulam	Dr A Krishnaveni Professor and Head of the Department of Community Medicine, Principal of Government Medical College, Srikakulam
	Homibhabha Cancer Hospital and Research Centre, Visakhapatnam	Dr Avinash Bonda Consultant, Medical Oncology
	Mahatma Gandhi Cancer Hospital and Research Institute, Visakhapatnam	Dr Rajini Priya Consultant, Medical Oncology
	Secondary	
	Area Hospital, Anakapalle	Dr Praveen Varma, Consultant Paediatrician
	District Hospital, Paderu	Dr K. Krishna Rao, Medical Superintendent
	Area Hospital, Narsipatnam	Dr Raghavendra, Consultant Paediatrician
	OMNI RK Superspeciality Hospital, Visakhapatnam	Dr Rajasekhar, Consultant Paediatrician Dr Ramya, Paediatric Resident
	Rainbow Children's Hospital, Visakhapatnam	Mr Manoj, Operational Manager
Arunachal Pradesh	**Tertiary**	
	Tomo Riba Institute of Health and Medical Sciences, Naharlagun	Dr Sopai Tawsik, Senior Pathologist, Department of Pathology Dr Hage Sonia, Nodal Officer, Pain and Palliative Unit
	Secondary	
	Bakin Pertin General Hospital, Pasighat	Dr Kaling Jerang, Senior Pathologist
	Rama Krishna Mission Hospital, Itanagar	Dr Tasso Byai, Consultant Paediatrician
Assam	**Tertiary**	
	Gauhati Medical College, Guwahati	Dr Jina Bhattacharya, Professor, Department of Haematology
	Sri Sankardeva Netralaya, Guwahati	Dr Kasturi Bhattacharjee,

State	Participating Hospitals	Staff
		Senior Consultant and Director (Clinical & Academics)
	Dr B Borooah Cancer Institute, Guwahati	Dr Munlima Hazarika, Prof & Incharge, Department of Medical and Paediatric Oncology
	North East Cancer Hospital and Research Institute, Guwahati	Dr Ilawati Longkumer, Biochemist
	Secondary	
	Sonapur District Hospital, Kamrup	Dr Ulupi Phukan Baruah, Medical Superintendent
	Tolaram Bafna hospital, Guwahati	Dr Kandarpa Das, Medical Superintendent
	Health City hospital, Guwahati	Dr Himanshu Baishya, Deputy Medical Superintendent
	Guwahati Neurological Research Centre, Guwahati	Dr Uttam Hanse, Consultant Paediatrician
Bihar	**Tertiary**	
	All India Institute of Medical Sciences, Patna	Dr Lokesh Tiwari, Head of the Department of Pediatrics Dr Chandra Mohan Kumar, Additional Professor, Department of Pediatrics Dr Prijanjali Singh, Additional Professor, Department of Radiotherapy
	Indira Gandhi Institute of Medical Sciences (IGIMS), Patna	Dr Dinesh Kumar Sinha, Additional Professor, Department of Radiation Oncology
	Paras- Hai Medicare and Research Institute Hospital, Patna	Dr Avinash Kumar Singh, Senior Consultant, Department of Haematology, Haemato-oncology and Bone Marrow Transplant
	Secondary	
	Homi Bhabha Cancer Hospital and Research Center, Muzaffarpur	Dr Gunjesh Kumar Singh, Consultant, Medical Oncology
Chandigarh	**Tertiary**	
	Government Medical College & Hospital -32, Chandigarh	Dr Awadhesh Kumar Pandey, Professor & Head of the Department of Radiation Oncology
	Post Graduate Institute of Medical Education & Research, Chandigarh	Dr Amita Trehan, Professor and In-Charge, Paediatric Haemato-Oncology Unit, Department of Paediatrics
	Secondary	
	Government Multi Specialty Hospital -16, Chandigarh	Dr Amandeep Kang, Director, Health and Family Welfare
Chhattisgarh	**Tertiary**	

State	Participating Hospitals	Staff
	All India Institute of Medical Sciences, Raipur	Dr Sunil Natha Jondhale, Associate Professor, Department of Paediatrics
	Pt JNM medical college and Dr B R Ambedkar Hospital, Raipur	Dr Manjula Beck, Professor, Department of Radiation Oncology
	Chhattisgarh Institute of Medical Sciences, Bilaspur	Dr Chandrahas Dhruw, Assistant Professor, Department of Radiotherapy
	BALCO Medical centre, Raipur	Dr Jayesh Sharma, Chief of Medical Services
	Sanjeevani CBCC USA Cancer Hospital, Raipur	Dr Aniket Thoke, Senior Medical Oncologist Dr Vikas Goyal, Senior Haematologist and Hemato-oncologist
	Secondary	
	Mittal Hospital, Raipur	Dr Suman Mittal, Consultant, Medical Oncology
Gujarat	**Tertiary**	
	The Gujarat Cancer & Research Institute, Ahmedabad	Dr Shashank Pandya, Director, Department of Surgical Oncology Dr Anand Shah, Assistant Professor, Department of Community Oncology and Medical Records
	Lions Cancer Care institute, Surat	Dr Sanjay Nandeshwar, Medical Director
	Gujarat Medical Education and Research Society (GMERS) Medical College, Gandhinagar	Dr Ekta Dalal, Associate Professor, Department of Paediatrics
	Secondary	
	District Hospital - Mehsana, Mehsana District	Dr Sakshi Prabodh, Consultant Paediatrician
	District Hospital - Lunavada, Mahisagar District	Dr Shah, Medical Superintendent
Haryana	**Tertiary**	
	BPS Government Medical College for Women, Haryana	Dr Manoj Rawal, Associate Professor and Head of the Department of Paediatrics
	Pt. B.D. Sharma, PGIMS, Rohtak	Dr Alka Yadav, Professor, Department of Paediatrics
	Fortis Memorial Research Institute (FMRI), Gurugram	Dr Vikas Dua, Director And Head, Paediatric Hemato-Oncology and Bone Marrow Transplant
	Medanta Hospital, Gurugram	Dr Neha Rastogi, Senior Consultant, Department of Medical and Haemato-oncology
	ARTEMIS, Gurugram	Dr Padam Yadav, Consultant Paediatrician

State	Participating Hospitals	Staff
	Kalpana Chawla Medical College, Karnal	Dr Jugesh Chhatwal, Professor and Head of the Department of Paediatrics
	Shaheed Hasan Khan Mewati Government Medical College, Mewat	Dr Arti Dhingra, Professor and Head of the Department of Paediatrics
	Maharaja Agarsen, Medical College, Agroha	Dr Surendra Kumar, Assistant Professor, Department of Paediatrics
	SGT Medical College, Budhera Gurugram	Dr Pankaj Abrol, Professor and Head of the Department of Paediatrics
	Secondary	
	Kainos Hospital, Rohtak	Dr Harmeet Singh, Consultant Radiation Oncologist
Jammu and Kashmir	**Tertiary**	
	Sher-I-Kashmir Institute of Medical Sciences, Srinagar	Dr Arshad Manzoor Najmi Associate Professor, Department of Radiation Oncology
	S.M.H.S. Hospital, Srinagar, affiliated with Government Medical College Srinagar	Dr Ashfaq Hafiz, Lecturer, Department of Radiation Oncology
	District Hospital, Anantnag	Dr Shahid Bashir Wani, Assistant Professor, Department of Radiotherapy
	District Hospital, Baramulla	Prof. Mohammad Maqbool Lone, Professor and Head of the Department of Radiation Oncology
	Secondary	
	District Hospital, Pulwama	Dr Ishtiyak Ahmad Dar, Medical Officer and Radiation Oncologist
	District Hospital, Kupwara	Dr Masoodi, Consultant Physician
Jharkhand	**Tertiary**	
	Rajendra Institute of Medical Sciences, Ranchi	Dr Rohit Kumar Jha, Assistant Professor and Head of the Department of Surgical Oncology Dr Hirendra Birua, Associate Professor, Department of Paediatric Surgery
	HCG Abdur Razzaque Ansari Cancer Hospital, Ranchi	Vijay Tomar, Chief Executive Officer (CEO)
	Meherbai Tata Memorial Hospital, Jamshedpur	Dr Abhishek Thakur, Deputy Medical Superintendent
	Secondary	

State	Participating Hospitals	Staff
	Sheikh Bhikhari Medical College is attached to Sardar hospital, Hazaribagh	Dr Chhitiz Anand, Assistant Professor, Department of Paediatrics
	Rani Children Hospital, Ranchi	Mr Hasan M Usmani, Hospital Administrator
Karnataka	**Tertiary**	
	Kidwai Memorial Institute of Oncology, Bengaluru	Dr C Ramachandra, Director Dr Arun Kumar AR, Associate Professor and Incharge Head of the Department of Paediatric Oncology
	St Johns Medical College Hospital, Bengaluru	Dr Anand Prakash, Professor and Head, Division of Paediatric Haematology
	Kasturba Medical College, Mangaluru	Dr Harsha Prasada L, Chief, Division of Paediatric Haematology and Oncology
	KLES Dr Prabhakar Kore Hospital & M.R.C, Belagavi	Dr Abhilasha Sampagar, Paediatric Haemato-oncologist and Associate Professor, Department of Paediatrics
	Kasturba Medical College, Manipal	Dr Vasudev Bhat, Associate Professor and Head, Division of Paediatric Haematology and Oncology
	Secondary	
	Mysore Medical College and Research Institute, Mysore	Dr S Mukesh, Assistant Professor, Department of Radiotherapy
	SNR District Hospital, Kolar	Dr B.C.Balasunder, Regional Medical Officer (RMO)
	Vijayapura District Hospital, Vijayapura	Dr Ravikumar Baradol, Senior Consultant Paediatrician
	Jayanagar General Hospital, Jayanagar, Bengaluru	Dr Raghuramaiah K N Senior Specialist Paediatrician
	KC General Hospital, Malleswaram, Bengaluru	Dr S R Lakshmipathy Senior Specialist Paediatrician
	District Hospital, Ramanagara	Dr Shashidhar S District Surgeon
Kerala	**Tertiary**	
	Government Medical College, Calicut	Dr Sheetal K, Assistant Professor, Department of Paediatrics
	Amrita Institute of Medical Sciences, Kochi	Dr Rema G, Assistant Professor,

State	Participating Hospitals	Staff
		Division of Clinical Haematology and Stem Cell Transplantation
	MVR Cancer Centre & Research Institute, Kozhikode	Dr Yamini Krishnan, Senior Consultant and Head of the Department of Paediatric Oncology
	VPS Lakeshore Hospital, Kochi	Dr V P Gangadharan, Senior Consultant and Head of the Department of Medical and Paediatric Oncology
	Indira Gandhi Co-operative Hospital, Kochi	Dr V P Gangadharan, Senior Consultant and Head of the Department of Medical and Paediatric Oncology
	Malabar Cancer Centre, Thalassery	Dr Jithin T K, Assistant Professor, Department of Paediatric Oncology
	Regional Cancer Centre, Thiruvananthapuram	Dr Priya Kumari T, Professor and Head of the Department of Paediatric Oncology
	Amala Institute of Medical Sciences, Thrissur	Dr Sunu Lazar Cyriac, Consultant and Assistant Professor, Department of Medical Oncology and Haematology
	Government Medical college, Pariyaram, Kannur	Dr Urmila K V, Associate Professor, Department of Paediatrics
	KIMS Hospital, Thiruvananthapuram	Dr Shwetha Seetharam, Associate Consultant, Department of Paediatric Oncology
	Secondary	
	Early Cancer Detection Centre, Palakadu	Dr Rekha S R, Resident Medical Officer
	District Hospital, Thrissur	Dr Usha Shree Warrior, Consultant and Head of the Department of Radiotherapy
	Beach hospital, Kozhikode	Dr Sandeep M, Junior Consultant, Department of Radiotherapy
	District Hospital, Kanjangad	Dr Raju Mathew Cyriac, Junior Consultant, Department of Clinical Oncology
	General Hospital, Ernakulam	Dr Jiss Joy, Junior Consultant, Department of Radiation Oncology
Madhya Pradesh	**Tertiary**	
	All India Institute of Medical Sciences, Bhopal	Prof Shikha Malik,

State	Participating Hospitals	Staff
		Professor and Head of the Department of Pediatrics Dr Narendra Kumar Chaudhary MD, IAP Fellowship and FNB (Pediatric hhaematology-oncology) Associate Professor Department of Pediatrics
	Government Medical College, Indore	Dr Prachi Chaudhary, Associate Professor, Department of Pediatrics
	Gandhi Medical College, Bhopal	Dr Shweta Sharma, Associate Professor, Department of Paediatrics
	Cancer Center, Shri Aurobindo Institute of Medical Sciences, Indore	Dr Col Prakash Chitalkar, Professor and Head of the Department of Medical Oncology
	JN Cancer Hospital, Bhopal	Dr Prateek Tiwari, Senior Consultant, Division of Medical and Paediatric Haemato-oncology
	Secondary	
	District Hospital, Shahdol	Dr Nishant Prabhakar, Assistant Professor, Department of Paediatrics
	Kushabhau Thakre Govt District Hospital, Rewa	Dr Gaurav Tripathi, Medical Officer
	District hospital, Ujjain	Dr Muktaditya Sharma, Medical Officer
	Samarpan Clinic, Balaghat	Dr Ashish Giri, Consultant Paediatrician
	Rainbow Children Hospital, Bhopal	Dr Rajan Khetarpal, Consultant Paediatrician
Maharashtra	**Tertiary**	
	Lokmanya Tilak Municipal General Hospital and Lokmanya Tilak Municipal Medical College, Sion	Dr Nisha Iyer, Assistant Professor, Division of Paediatric Haemato-oncology
	Indrayani Hospital and Cancer Institute, Alandi, Pune	Dr Nitin Gosavi, Chief Medical Officer
	Government Cancer Hospital, Aurangabad	Dr Aditi Lingayat, Professor and Head of the Department of Paediatric Oncology
	Rashtra Sant Tukdoji Maharaj Regional Cancer (RST) Hospital, Nagpur	Dr Kartar Singh, Head of the Department of Radiology

State	Participating Hospitals	Staff
	Bai Jerbai Wadia Hospital for Children, Mumbai	Dr Sangeeta Mudaliar, Consultant and Head of the Department of Paediatric Haemato-oncology
	BKL Walawalkar Hospital, Dervan	Dr Suvarna Patil, Medical Director
	National Cancer Institute, Nagpur	Dr Prakash Kakani, Medical Superintendent
	MGM Medical College and Hospital, Aurangabad	Dr Tushar Idhate, Assistant Professor, Department of Paediatrics
	Regional Referral Hospital, Nashik	Dr Ashok Thorat, Civil Surgeon M S Gyaencology
	District Civil Hospital, Gadchiroli	Dr Anil Rudey, Civil Surgeon
	Tata Memorial Centre, Mumbai	Dr Nirmalya Roy Moulik, Assistant Professor, Department of Paediatric Oncology
	Secondary	
	Bharati Vidyapeeth Hospital, Pune	Dr Vibha Sanjay Bafna, Assistant Professor, Department of Paediatrics
Manipur	**Tertiary**	
	Regional Institute of Medical Sciences, Imphal	Dr Y Sobita Devi, Assistant Professor, Department of Radiotherapy
	Jawaharlal Nehru Institute of Medical Sciences, Imphal	Prof. N Kameshore Singh, Professor and Head of the Department of Paediatrics
	Mother care and Children Hospital and Research Institute, Imphal	Dr Asit Kumar Debnath, Medical Director
	Babina Oncology Hospital, Waiton	Dr Veerendra Hiremath, Facility Director
	Secondary	
	CHC, Churachandpur	Dr Akai Haokip, Medical Officer (Paediatrics)
Meghalaya	**Tertiary**	
	North Eastern Indira Gandhi National Institute of Health and Medical Sciences (NEIGRIHMS), Shillong	Dr Caleb Harris Associate Professor, Department of Surgical Oncology
	Secondary	
	Civil Hospital, Shillong	Dr Anisha Mawlong,

State	Participating Hospitals	Staff
		Specialist and Head of the Department of Radiation Oncology
	Ganesh Das Hospital, Shillong	Dr P Khongsni, Specialist, Department of Surgery Dr J Swett, Specialist, Department of Paediatrics
	Woodland Hospital, Shillong	Dr Cliffton Sutnga, Consultant Medical Oncologist
	The Children's Hospital, Shillong	Dr Debashish Das, Medical Director
	Nazareth Hospital, Shillong	Dr Santanu Deb, Consultant and Head of the Department of Paediatrics
Mizoram	**Tertiary**	
	Mizoram State Cancer Institute, Aizawl	Dr Jeremy L Pautu, Head of the Department of Medical Oncology
	Zoram Medical College, Falkawn	Dr F. Elizabeth Lalhmangaihzuali, Associate Professor and Head of the Department (Incharge) of Paediatrics
	Civil Hospital, Aizawl	Dr Lalchhuankimi, Consultant and Head of the Department of Paediatrics
	Synod Hospital, Aizawl	Dr John Malsawma, Deputy Medical Superintendent
	Ebenezer Medical Centre, Aizawl	Dr Lalmalsawmi Hmar, Consultant Paediatrician
	Secondary	
	Civil Hospital, Lunglei	Dr James Lalzuitluanga Chongthu, Consultant Radiation Oncologist
	Kulikawn Hospital, Aizawl	Dr Lalduhawmi Pachuau, Medical Officer (Paediatrics)
	John Williams Hospital, Lunglei	Dr Zochhuani Ralte (MBBS, DCH), Medical Officer and Paediatrician
	LRM Hospital, Aizawl	Dr K Lalawmpuia, Consultant Paediatrician
Nagaland	**Tertiary**	
	Christian Institute Of Health Sciences & Research, Dimapur	Dr Sulanthung Kikon, Consultant Paediatrician
	Eden Medical Centre, Dimapur	Dr Moatoshi Aier, Laboratory Director

State	Participating Hospitals	Staff
	Zion Hospital & Research Centre, Dimapur	Dr Akumtoshi, Consultant Paediatrician
	Secondary	
	Oking Hospital, Kohima	Dr Ekonthung Mozhui, Consultant Paediatrician
	Bethel Medical Center, Kohima	Dr Rokolhoukho Sirie, Consultant Paediatrician
	Naga Hospital Authority, Kohima	Dr Khriemenuo, Senior Consultant, Department of Paediatrics
New Delhi	**Tertiary**	
	All India Institute of Medical Sciences, New Delhi	Dr Rachna Seth, Professor Division of Pediatric Oncology
	Lady Hardinge Medical College, Kalawati Saran Children's Hospital (KSCH), New Delhi	Dr Varinder Singh, Director-Professor, Department of Pediatrics
	Max Super Speciality Hospital, Saket, New Delhi	Dr Ramandeep Arora, Senior Consultant
	Maulana Azad Medical College, Lok Nayak Hospital (LNH), New Delhi	Dr Puneet Kaur Sahi, Assistant Professor, Department of Paediatrics
	Vardhman Mahavir Medical College (VMMC), Safdarjung Hospital (SJH), New Delhi	Dr Amitabh Singh, Associate Professor, Department of Paediatrics
	University College of Medical Sciences (UCMS), Guru Teg Bahadur Hospital (GTB), New Delhi	Dr Pooja Dewan, Professor, Department of Paediatrics
	Sir Ganga Ram Hospital, New Delhi	Dr Divij Sachdeva, Senior Resident, Division of Pediatric haematology-oncology and Bone Marrow Transplantation
	BLK MAX Super Speciality Hospital, New Delhi	Dr Vipin Khandelwal, Consultant, Division of Paediatric Haemato-oncology
	Rajiv Gandhi Cancer Institute, New Delhi	Dr Gauri Kapoor, Director and Head of the Department of Pediatric Hematology - Oncology Ms. Swarnima Jaitley, Head, Philanthropic Services

State	Participating Hospitals	Staff
	Dr Ram Manohar Lohia Hospital, New Delhi	Dr Alok Hemal, Professor, Department of Paediatrics
	Secondary	
	Hindu Rao Hospital, New Delhi	Dr Dinesh Yadav, Chief Medical Officer
	Chacha Nehru Bal Chikitsalaya, New Delhi	Dr Sanghamitra Ray, Consultant Paediatrician
	Deen Dayal Upadhyay Hospital, New Delhi	Dr Ritu Chawla, Consultant Paediatrician
	Swami Dayanand Hospital, New Delhi	Dr D K Jha, Consultant Paediatrician and Chief Medical Officer
	St Stephens Hospital, New Delhi	Dr Surbhi Gupta, Consultant
	Mata Chanan Devi Hospital, New Delhi	Dr C P Sachdev, Senior Consultant and Head of the Department of Paediatrics
	Maharaja Agrasen Hospital, New Delhi	Dr Shobha Sehgal, Deputy Medical Superintendent
Odisha	**Tertiary**	
	All India Institute of Medical Sciences, Bhubaneswar	Dr Saroj Kumar Das Majumdar, Additional Professor, Department of Radiotherapy
	Sum Hospital, Bhubaneswar	Dr Saroj Panda, Professor, Department of Paediatric Oncology
	Acharya Harihar Regional Cancer Center, Cuttack	Dr Prasant Prida, Assistant Professor, Department of Medical Oncology
	Secondary	
	District Hospital, Cuttack	Dr Sudhanshu Kumar Giri, District Medical Officer and Superintendent
	District Hospital, Balasore	Dr Priya Kumar Ghosh, Additional Director
Puducherry	**Tertiary**	
	Indira Gandhi Medical College and Research Institute, Puducherry	Dr P Sriram, Professor and Head of the Department of Paediatrics
	Pondicherry Institute of Medical Science, Puducherry	Dr Peter Prasanth Kumar Kommu, Professor, Department of Paediatrics
	JIPMER, Regional Cancer Centre, Puducherry	Dr Gunaseelan K, Professor and Head of the Department of Radiation Oncology

State	Participating Hospitals	Staff
Punjab	**Tertiary**	
	Guru Gobind Singh Medical College, Faridkot (Government)	Dr Pradeep Garg, Associate Professor and Head of the Department of Radiation Oncology
	Christian Medical College and Hospital, Ludhiana	Dr M Joseph John, Professor and Head of the Department of Clinical Haematology
	Advanced Cancer Diagnostic Treatment & Research Centre, Bathinda (Government)	Dr Karuna Assistant Professor, Department of Radiation Oncology
	Fortis Hospital, Mohali	Dr Ritu Pankaj, Senior Consultant, Department of Pathology
	Patel Cancer & Superspeciality Hospital, Jalandhar	Dr Jitender Kumar Arora, Consultant Medical Oncologist
	Government Medical College, Patiala	Dr Vijay Kumar Bodal, Professor of Pathology Dr Raja Paramjeet Singh Banipal Professor and Head of the Department of Radiation Oncology
	Secondary	
	Civil Hospital, Ropar	Dr Gurpreet Kaur, Paediatrician
	Civil Hospital, Nawansher	Dr Mandeep Kamal, Senior Medical Officer
	Civil Hospital, Pathankot	Dr Abhay Garg, Medical Officer, Specialist (Paediatrics)
	Civil Hospital, Amritsar	Dr Chander Mohan, Senior Medical Officer
	Civil Hospital, Firozpur	Dr David, Paediatrician
	Civil Hospital, Mansa	Dr Vikram Singh Katodia, Paediatrician
	Civil Hospital, Jalandhar	Dr Sahil Vikas, Medical Officer, Specialist (Paediatrics)
Rajasthan	**Tertiary**	
	All India Institute of Medical Sciences, Jodhpur	Dr Puneet Pareek, Additional Professor, Department of Radiation Oncology
	S N Medical College and Attached Hospitals, Jodhpur	Dr Vikas Katewa, Assistant Professor, Department of Paediatrics
	SMS Medical College and Hospitals, Jaipur	Dr Pawan Kumar Sulaniya, Associate Professor,

State	Participating Hospitals	Staff
		Department of Paediatrics
	SP Medical College and Hospitals, Bikaner	Dr Surendra Beniwal, Professor, Department of Medical Oncology
	RNT Medical College and Attached Hospitals, Udaipur	Dr Vivek Arora, Professor and Head of the Department of Paediatrics
	Secondary	
	Government Bangar District Hospital, Pali	Dr Vikas Jain, Medical Officer
Sikkim	**Tertiary**	
	Sikkim Manipal Institute of Medical Sciences, Tadong, Gangtok	Dr Yogesh Verma, Medical Superintendent
	Sir Thutob Namgyal Memorial Referral Hospital, Gangtok	Dr Tseten W Bhutia Chief Consultant and Head of the Department of Pathology
	Secondary	
	District Hospital, Singtam	Dr Sabinaa Laishram, Pathologist
Tamil Nadu	**Tertiary**	
	Cancer Institute (W.I.A), Chennai	Dr Ventraman Radhakrishnan, Professor, Department of Medical Oncology
	Institute of Child Health, Chennai	Dr Aruna Rajendran, Assistant Professor, Department of Pediatric Hematology and Oncology
	Kanchi Kamakoti Child Trust Hospital, Chennai	Dr Arathi Srinivasan, Consultant Paediatric Oncologist
	Meenakshi Mission Hospital, Madurai	Dr Kasi Viswanathan, Head of the Department of Pediatric Hematology and Oncology
	Secondary	
	PSG Hospital, Coimbatore	Dr Rumesh Chandar, Assistant Professor, Department of Medical Oncology
Telangana	**Tertiary**	
	MNJ Institute of Oncology & RCC, Hyderabad	Dr P Krishna Chaitanya, Associate Professor
	ESIC Hospital, Hyderabad	Dr Ratna Gosain, Consultant Pathologist
	Rainbow Children's Hospital, Hyderabad	Dr Sirisha Rani S, Senior Consultant, Division of Paediatric Hematology, Oncology and Bone Marrow Transplant

State	Participating Hospitals	Staff
	Nizam's Institute of Medical Sciences, Hyderabad	Dr Sadashivudu Gundeti, Additional Professor and Head of the Department of Medical Oncology
	Basavatarakam Indo American Cancer Hospital & Research Institute, Hyderabad	Dr K. Kalpana Raghunath, Associate Director and Principal Investigator (HBCR)
	Secondary	
	Rangareddy District, Hospital	Dr A. Varadhachary, Superintendent
	Government District Hospital, Bhongir	Dr B. Venkateshwarlu, Paediatrics, Civil Surgeon Specialist
	District Hospital, Sangareddy	Dr Ashok Muthkani, Paediatrics, Civil Surgeon Specialist
	CARE Hospitals, Hyderabad	Dr A M V R Narendra, Senior Consultant Hematology, Haemato-oncology and Bone Marrow Transplant
	Malla Reddy Hospital, Hyderabad	Dr Swapna Jilla, Senior Consultant and Head of the Department of Radiation Oncology
Tripura	**Tertiary**	
	ABV Regional Cancer Centre (Nodal Institution), Agartala	Dr Goutam Majumder, Medical superintendent
	Agartala Government Medical College & Govind Ballabh Pant Hospital, Agartala	Dr Sujit Kumar Chakraborty, Associate Professor, Department of Paediatrics
	Indira Gandhi Memorial Hospital, Agartala	Ms. Sudipa Paul, Hospital Administrator
	Tripura Medical College, Hapania	Prof. Jayanta Kumar Podder , Head of the Department of Pediatrics
	ILS Hospital, Agartala	Dr Archana Jain (Datta), Deputy Medical Superintendent
	Secondary	
	District Hospital South, Shantirbazar	Mr. Sanjib Das, Assistant Hospital Administrator
	District Hospital Gomati, Udaipur	Dr Swapan Chakma, Clinical Microbiologist
	District Hospital Unakoti, Kailasahar	Ms. Sutapa Debnath, Nursing Superintendent
	District Hospital Dhalai, Kulai	Medical Superintendent
	District Hospital North, Dharmanagar	Dr Dipak Chandra Halder, Medical Superintendent
Uttar Pradesh	**Tertiary**	
	Institute of Medical Sciences - Banaras Hindu University, Varanasi	Dr Vineeta Gupta, Professor, Department of Paediatrics,

State	Participating Hospitals	Staff
	Homi Bhabha Cancer hospital, Varanasi	Dr Vikramjit Singh Kanwar, Head/Chief of the Division of Pediatric Oncology
	King George Medical University, Lucknow	Dr Nishant Verma, Additional Professor, Department of Paediatrics
	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow	Dr Anshul Gupta, Associate Professor, Department of Haematology
	Super Speciality Paediatric Hospital & Post Graduate Teaching Institute, Noida	Dr Nita Radhakrishnan, Associate Professor and Head of the Department of Pediatric Hematology-Oncology
	Medical college, Meerut	Dr Navratan Gupta, Associate Professor, Department of Paediatrics
	Secondary	
	District hospital, GB Nagar	Dr Renu Agarwal, Chief Medical Officer
	District hospital, Agra	Dr BP Singh Kalyani, Senior Consultant, Anesthesiology
	District hospital, Mathura	Dr Bhrahmadev Bhaskar, Chief Medical Superintendent (CMS)
	Gorakhpur Hanuman Poddar Cancer Hospital, Gorakhpur	Dr Roopa Ganta, Consultant Head and Neck Oncosurgeon
Uttarakhand	**Tertiary**	
	All India Institute of Medical Sciences, Rishikesh	Dr Deepak Sundriyal, Assistant Professor, Department of Medical Oncology-Haematology
	Government Doon Medical College, Dehradun	Dr Ashok Kumar, Associate Professor, Department of Paediatrics
	Government Medical College, Srinagar, Pauri Garhwal	Dr Vyas Kumar Rathaur, Professor and Head of the Department of Paediatrics
	Himalayan Institute of Medical Sciences (Trust), Jollygrant	Dr Kunal Das, Associate Professor, Department of Haemeto-oncology
	Secondary	
	Rudrapur District Hospital, Uttarakhand	Dr Paras Agarwal, Medical Officer
	Ram Dutt Joshi Combined Government Hospital, Ramnagar	Dr Praveen Kumar Gupta, Consultant Paediatrician
	Shri Dev Suman Combined Hospital, Narendra Nagar, Tehri Garhwal	Dr Sunita, Senior Medical Officer, Paediatrician
	District Female Hospital, Haldwani	Dr Renu Agnihotri Paediatrician

State	Participating Hospitals	Staff
	HMG District Hospital, Haridwar	Dr Shashi Kant, Paediatrician
West Bengal	**Tertiary**	
	Chittaranjan National Cancer Institute, Kolkata	Dr Kalyan Kusum Mukherjee, Specialist Grade-I, Department of Medical Oncology
	Secondary	
	Ghatal Super Speciality Hospital, Paschim Medinipur	Dr Samrat Roy Chaudhury, Superintendent
	Darjeeling District Hospital	Dr Sounik Das, Medical Officer, Specialist, (Oncology)
	The Mission Hospital, Durgapur	Dr Partha Pal, Chief Medical Superintendent

Annexure 4 – List of state nodal officers

S.no	State	Name and designation
1	Gujarat	Dr Hiren D Bhagora, State Programme Officer NCD
2	Jammu and Kashmir	Dr Junaid Kousar, Nodal Officer
3	Tripura	Dr Supriya Mallik, State Programme Officer
4	Sikkim	Dr Sangeeta Pradhan, Additional Director & SPO NPCDCS
5	Nagaland	Dr Ebenezer Phesao, Medical Officer
6	Uttar Pradesh	Dr Alka Sharma, State Nodal Officer NCD
7	Punjab	Dr Sandeep Singh Gill, State Programme Officer
8	Kerala	Bipin K Gopal, Assistant Director, DHS, SNO-NCD
9	Chhattisgarh	Dr Sumi Jain, State Program Coordinator NCD
10	Puducherry	Dr R. Duraisamy, State Programme Officer
11	Maharashtra	Dr Padmaja Jogewar, Joint Director- NCD, Health Services
12	Arunachal Pradesh	Dr Lobsang Jampar, State Proramme Officer –NPCDCS
13	Jharkhand	Dr LR Pathak, State Nodal Officer, State NCD Cell
14	West Bengal	Dr Subhransu Sekhar Datta, Assistant Director, NCD II
15	Odisha	Dr Susanta Kumar Swain, Additional Director- NCD
16	Telangana	Dr Pushpa, Additional Director- NCD

Annexure 5 - Civil society organizations/non-governmental organizations

S.no	State	Name of CSO and responder
1	Haryana	Rajnish L Vohra, BansiVidya Memorial trust (Leukemia Crusaders)
2	Karnataka	Thanmaya Bekkalale, Founder Trustee & Secretary, Iksha Foundation
3	Kerala	Haris Kattakath, Chairman of The Board, Hope child cancer care foundation
4	Maharashtra	Deepali Pankaj, Program Lead – Development, St. Jude India Child Care Centers
5	Maharashtra	Dr Shubha Maudgal, Executive Director, Cancer Patients Aid Association
6	New Delhi	Poonam Bagai, Founder Chairman, Cankids Kidscan
7	New Delhi	Neelakshi Suryanarayan, President, RACE to rein-in-cancer
8	Orissa	Nitai Goura Panigrahi, Settler-cum-Chairman, Umeedein
9	West Bengal	Meheli Chakraborty, CEO, Ruma Abedona Hospice

Annexure 6 – Additional tables and figures

1. The proportion of secondary level facilities where a social worker accompanies the referred patient (%)

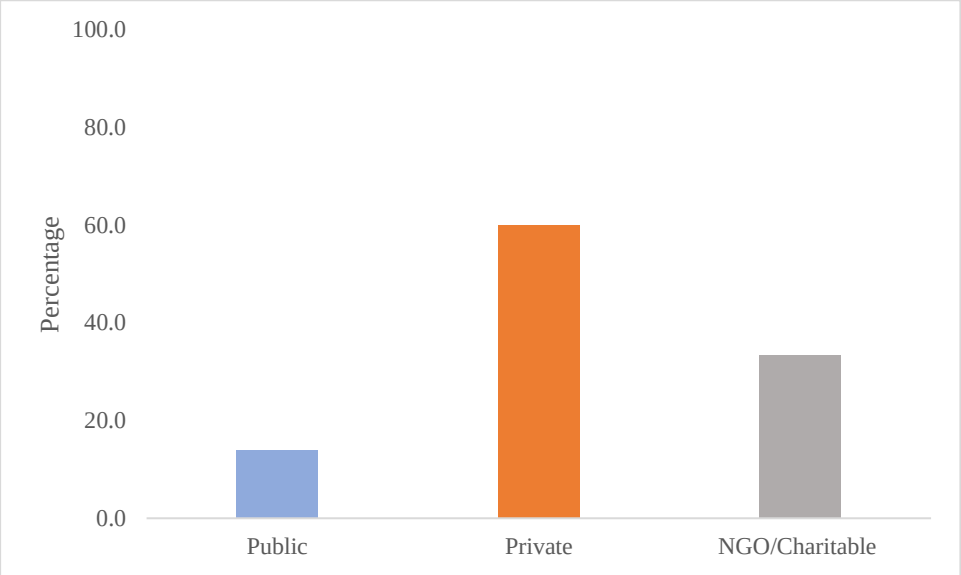

Fig. 33

2. Availability of childhood cancer treatment-related departments by the type of hospital

Table 16

S. No.	Department	Public (n = 77)						Private (n = 35)								NGOs/Charitable (n = 25)							
		Medical college hospital		Super speciality (oncology)		Multispeciality with dedicated oncology unit		Medical college hospital		Super speciality (oncology)		Multispeciality with dedicated oncology unit		Multispeciality without a dedicated general oncology unit		Medical college hospital		Super speciality (oncology)		Multispeciality with dedicated oncology unit		Multispeciality without a dedicated general oncology unit	
		53		12		12		11		8		14		2		6		12		5		2	
		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
1	Pediatric oncology	17	32.1	10	83.3	5	41.7	5	45.5	4	50	8	57.1	0	0	2	33.3	11	91.7	3	60.0	0	0
2	Medical oncology	18	34.0	9	75.0	8	66.7	7	63.6	7	87.5	8	57.1	0	0	3	50.0	10	83.3	2	40.0	0	0
3	Radiation oncology	34	64.2	11	91.7	7	58.3	7	63.6	7	87.5	10	71.4	0	0	4	66.7	11	91.7	2	40.0	0	0
4	Surgical oncology	23	43.4	11	91.7	7	58.3	8	72.7	6	75	10	71.4	0	0	4	66.7	10	83.3	3	60.0	0	0
5	Pediatric medicine	48	90.6	3	25.0	9	75.0	10	90.9	2	25	10	71.4	2	100	6	100	5	41.7	4	80.0	1	50
6	Medicine	35	66.0	3	25.0	9	75.0	9	81.8	3	37.5	7	50.0	1	50	4	66.7	3	25.0	2	40.0	2	100
7	Haematology	20	37.7	5	41.7	8	66.7	6	54.5	5	62.5	9	64.3	0	0	3	50.0	8	66.7	2	40.0	0	0
8	Pediatric surgery	37	69.8	2	16.7	9	75.0	8	72.7	2	25	9	64.3	1	50	4	66.7	5	41.7	2	40.0	0	0
9	Surgery	39	73.6	6	50.0	10	83.3	9	81.8	2	25	7	50.0	1	50	5	83.3	3	25.0	2	40.0	1	50
10	Ophthalmology	47	88.7	3	25.0	8	66.7	11	100.0	0	0	10	71.4	0	0	4	66.7	1	8.3	2	40.0	2	100
11	Musculoskeletal oncologist	3	5.7	3	25.0	1	8.3	2	18.2	1	12.5	4	28.6	0	0	1	16.7	5	41.7	3	60.0	0	0
12	Orthopaedics	48	90.6	3	25.0	10	83.3	10	90.9	1	12.5	11	78.6	1	50	5	83.3	3	25.0	3	60.0	1	50
13	Neurosurgery	36	67.9	3	25.0	8	66.7	9	81.8	2	25	12	85.7	0	0	4	66.7	5	41.7	1	20.0	0	0
14	Radiology	44	83.0	11	91.7	11	91.7	10	90.9	6	75	13	92.9	2	100	6	100	12	100	4	80.0	0	0
15	Nuclear medicine	15	28.3	7	58.3	5	41.7	4	36.4	5	62.5	9	64.3	0	0	1	16.7	10	83.3	0	0.0	0	0
16	Pathology	48	90.6	12	100.0	11	91.7	10	90.9	6	75	13	92.9	2	100	6	100	12	100	4	80.0	2	100
17	Palliative medicine	21	39.6	11	91.7	5	41.7	4	36.4	6	75	9	64.3	1	50	3	50.0	10	83.3	4	80.0	1	50

3. Availability of departments for childhood cancer treatment at secondary hospitals

Table 17

Department	Public n = 21						Private n = 13						NGO/charitable n = 02					
	Available and treating	%	Available but not treating	%	Not available	%	Available and treating	%	Available but not treating	%	Not available	%	Available and treating	%	Available but not treating	%	Not available	%
Paediatrics	15	71.4	4	19.0	2	9.5	11	84.6	2	15.4	-	-	2	100	-	-	-	-
Medical oncology	4	19.0	9	42.9	8	38.1	8	61.5	3	23.1	2	15.4	1	50	1	50	-	-
Radiation oncology	7	33.3	6	28.6	8	38.1	7	53.8	2	15.4	4	30.8	-	-	2	100	-	-
Surgical oncology	1	4.8	11	52.4	9	42.9	7	53.8	4	30.8	2	15.4	-	-	2	100	-	-
Medicine	15	71.4	6	28.6	-	-	10	76.9	2	15.4	1	7.7	-	-	2	100	-	-
Haematology	3	14.3	8	38.1	10	47.6	4	30.8	5	38.5	4	30.8	2	100	-	-	-	-
Paediatric surgery	6	28.6	7	33.3	8	38.1	5	38.5	6	46.2	2	15.4	1	50	1	50	-	-
Surgery	14	66.7	7	33.3	-	-	11	84.6	1	7.7	1	7.7	-	-	2	100	-	-
Orthopaedics	14	66.7	6	28.6	1	4.8	9	69.2	3	23.1	1	7.7	-	-	2	100	-	-
Neurosurgery	2	9.5	10	47.6	9	42.9	8	61.5	3	23.1	2	15.4	2	100	-	-	-	-
Radiology	13	61.9	8	38.1	0	0.0	11	84.6	1	7.7	1	7.7	2	100	-	-	-	-
Nuclear medicine	-	-	11	52.4	10	47.6	2	15.4	8	61.5	3	23.1	-	-	2	100	-	-
Pathology	16	76.2	5	23.8	-	-	10	76.9	2	15.4	1	7.7	2	100	-	-	-	-
Palliative medicine	14	66.7	3	14.3	4	19.0	5	38.5	4	30.8	4	30.8	-	-	2	100	-	
Ophthalmology	13	61.9	6	28.6	2	9.5	6	46.2	4	30.8	3	23.1	1	50	1	50	-	-

4. Waiting time for an appointment at different departments in tertiary hospitals

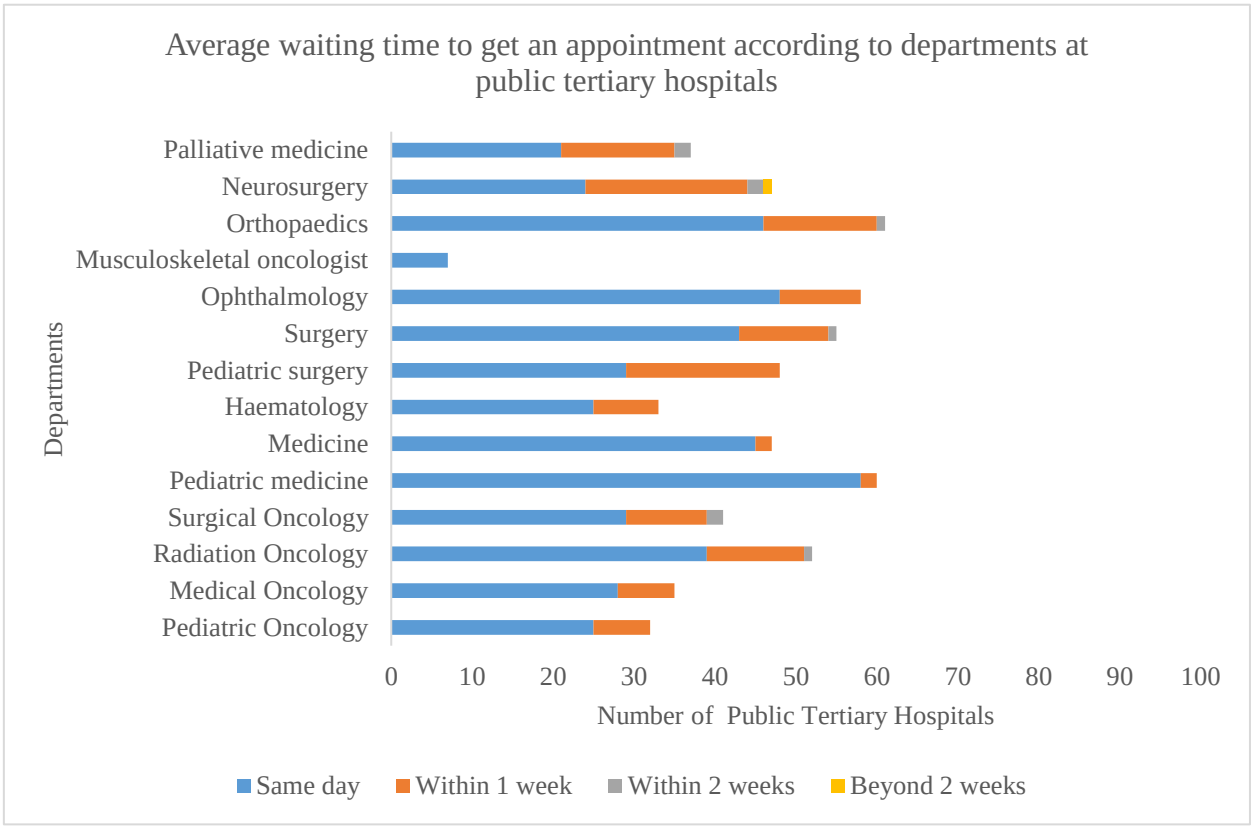

Fig. 34

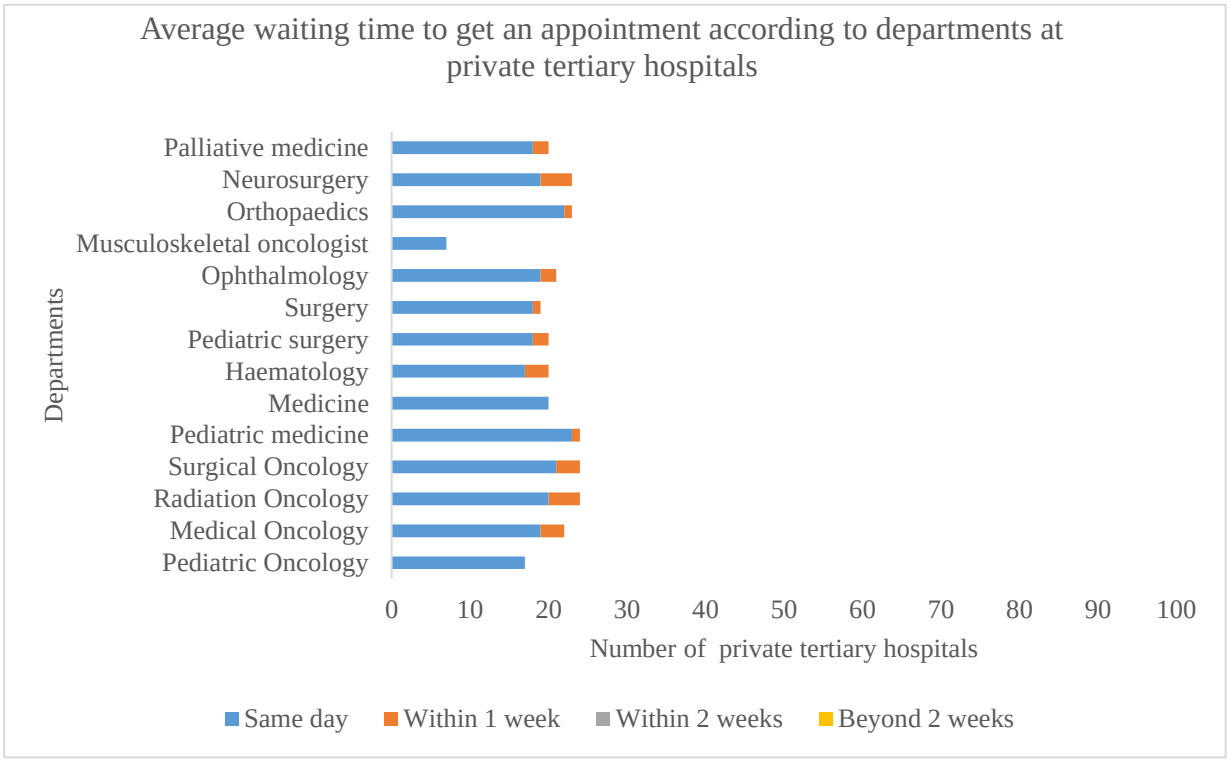

Fig. 35

5. Availability of referral for support facilities that were not available and mode of referral at tertiary hospitals

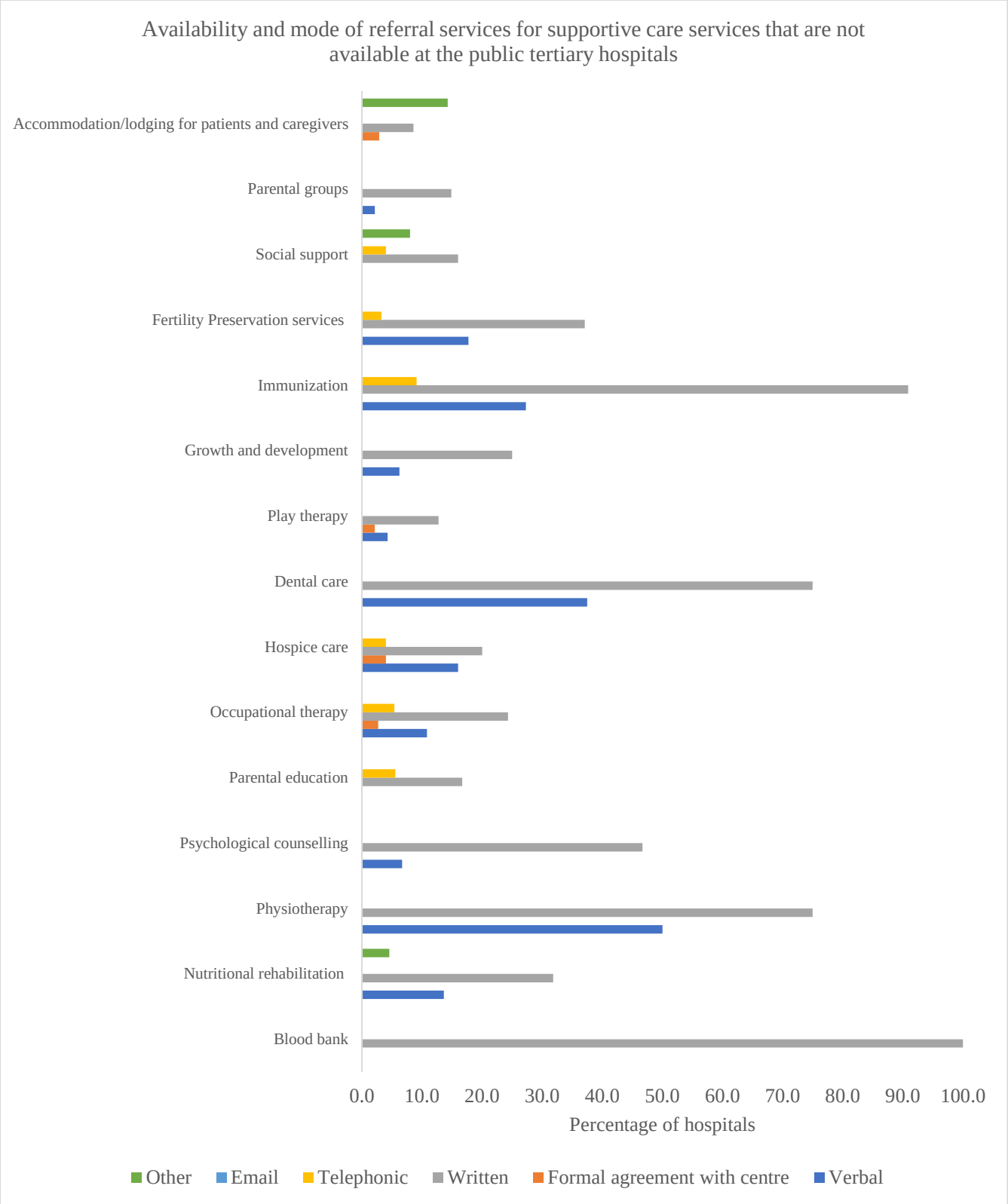

Fig. 36

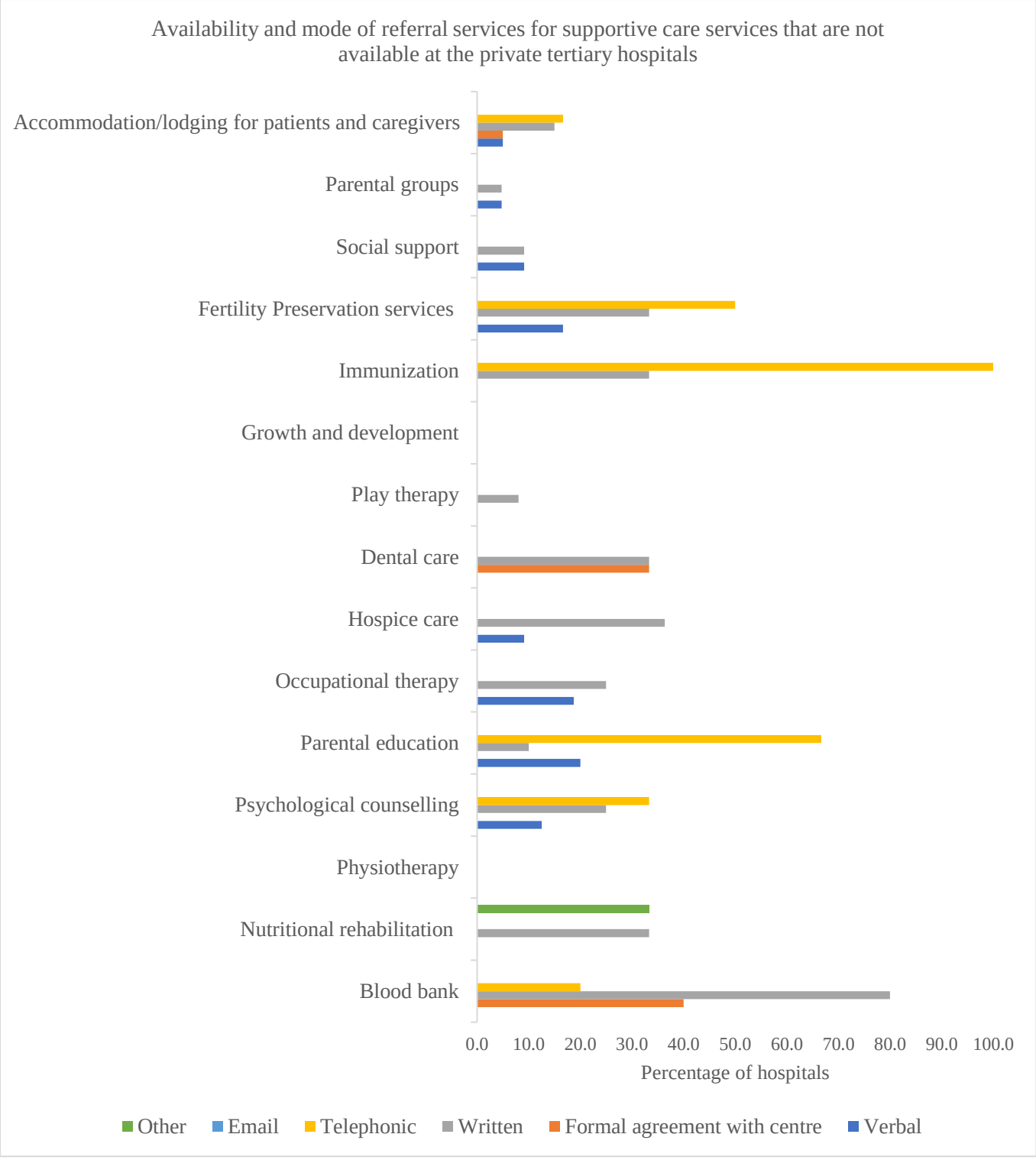
Availability and mode of referral services for supportive care services that are not available at the private tertiary hospitals
Accommodation/lodging for patients and caregivers
Parental groups
Social support
Fertility Preservation services
Immunization
Growth and development
Play therapy
Dental care
Hospice care
Occupational therapy
Parental education
Psychological counselling
Physiotherapy
Nutritional rehabilitation
Blood bank
0.0
10.0
20.0
30.0
40.0
50.0
60.0
70.0
80.0
90.0
100.0
Percentage of hospitals
Other
Email
Telephonic
Written
Formal agreement with centre
Verbal

Fig. 37

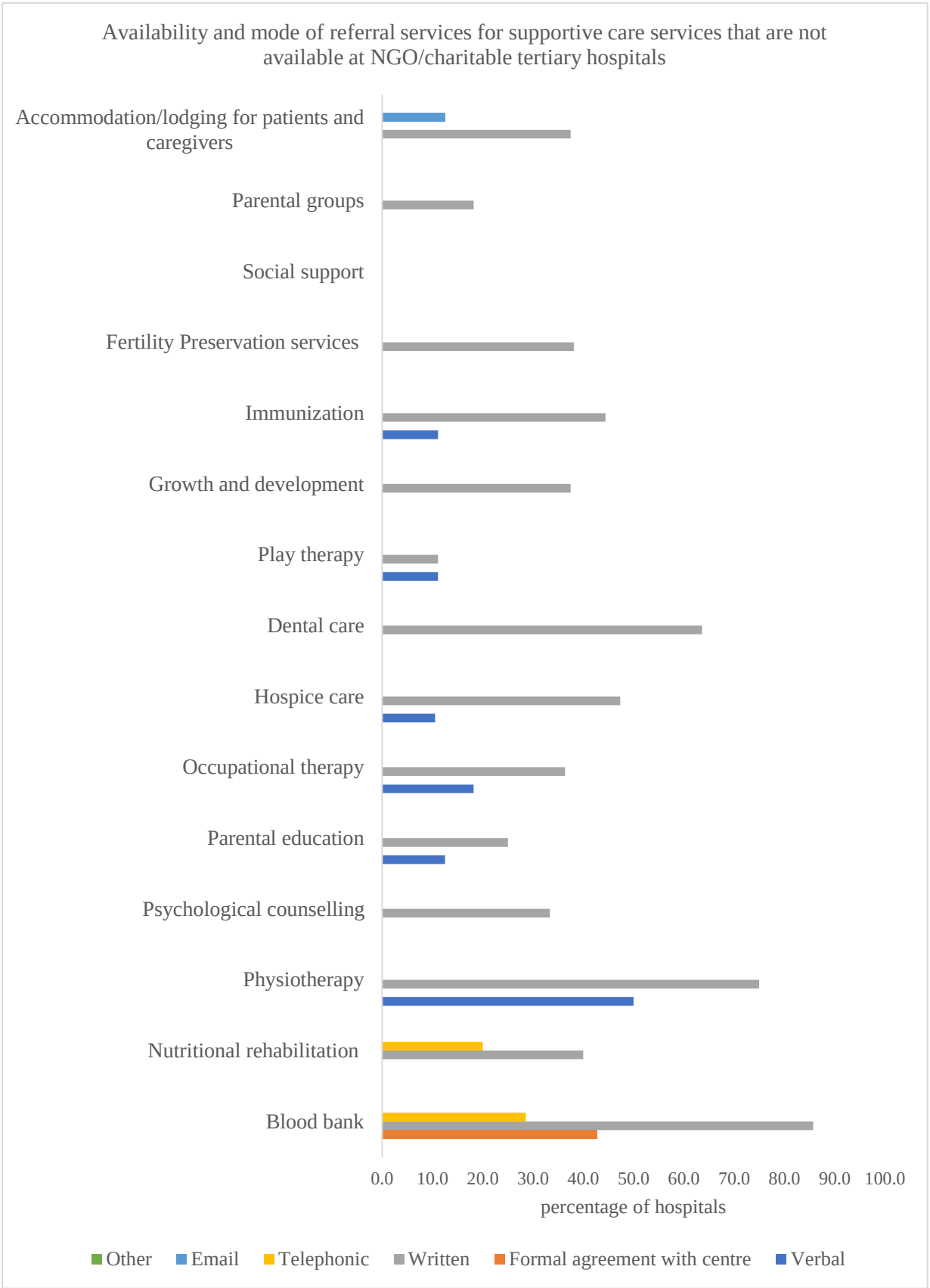
Availability and mode of referral services for supportive care services that are not available at NGO/charitable tertiary hospitals
Accommodation/lodging for patients and caregivers
Parental groups
Social support
Fertility Preservation services
Immunization
Growth and development
Play therapy
Dental care
Hospice care
Occupational therapy
Parental education
Psychological counselling
Physiotherapy
Nutritional rehabilitation
Blood bank
0.0 10.0 20.0 30.0 40.0 50.0 60.0 70.0 80.0 90.0 100.0
percentage of hospitals
Other
Email
Telephonic
Written
Formal agreement with centre
Verbal

Fig. 38

6. Average waiting time to avail of an appointment at the treating departments in secondary level hospitals

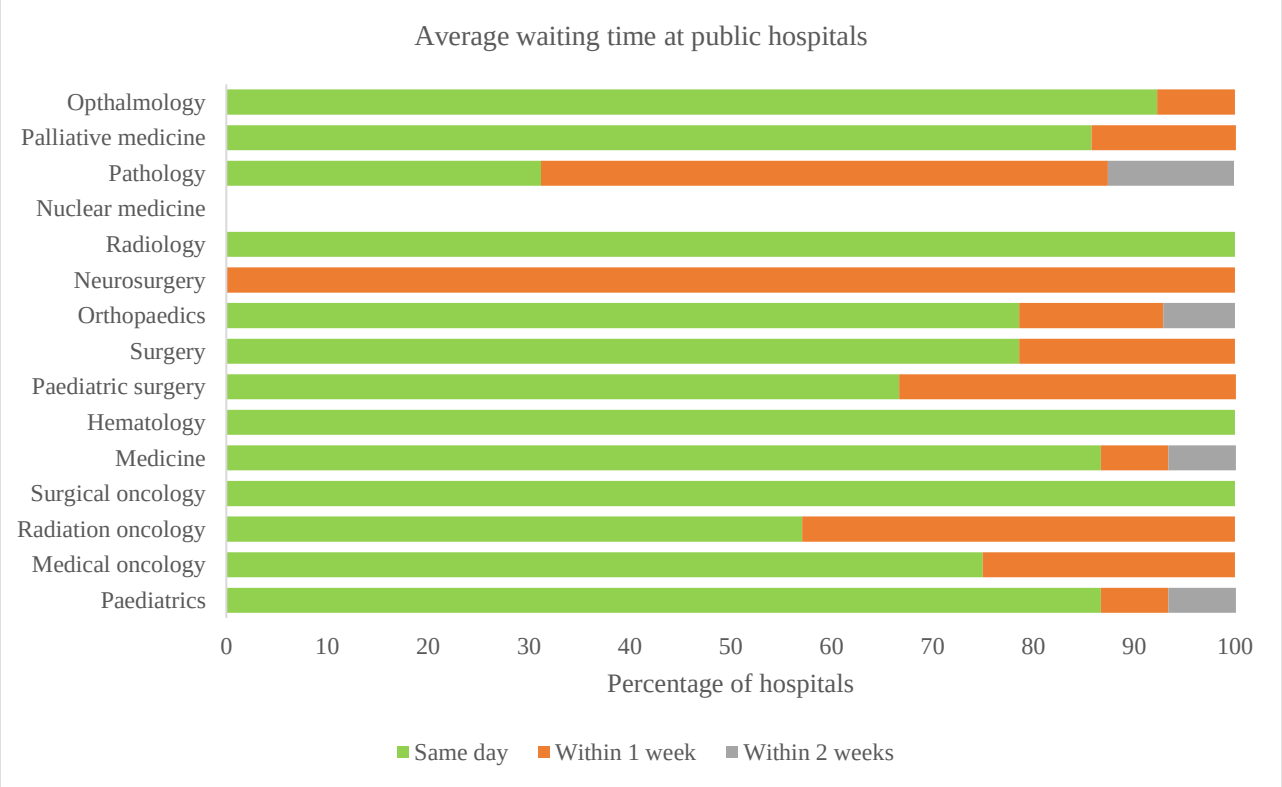

Fig. 39

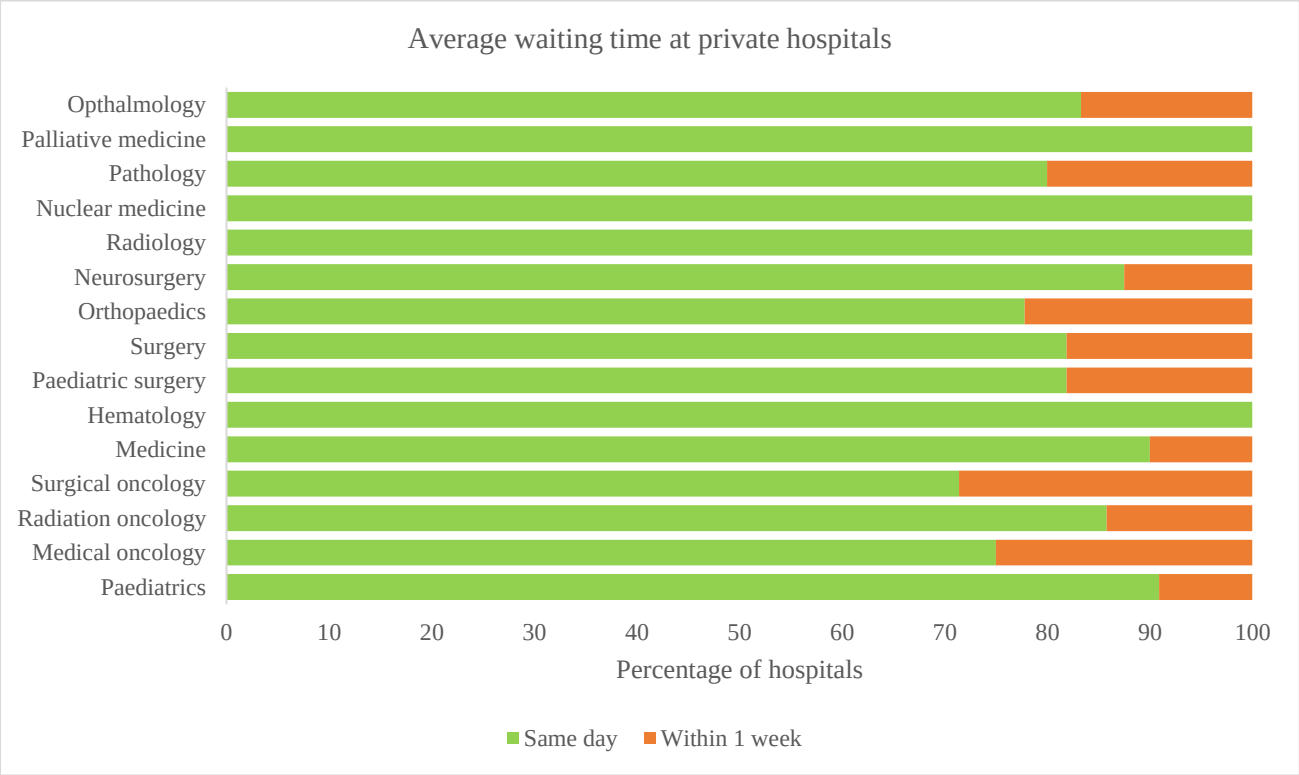

Fig. 40

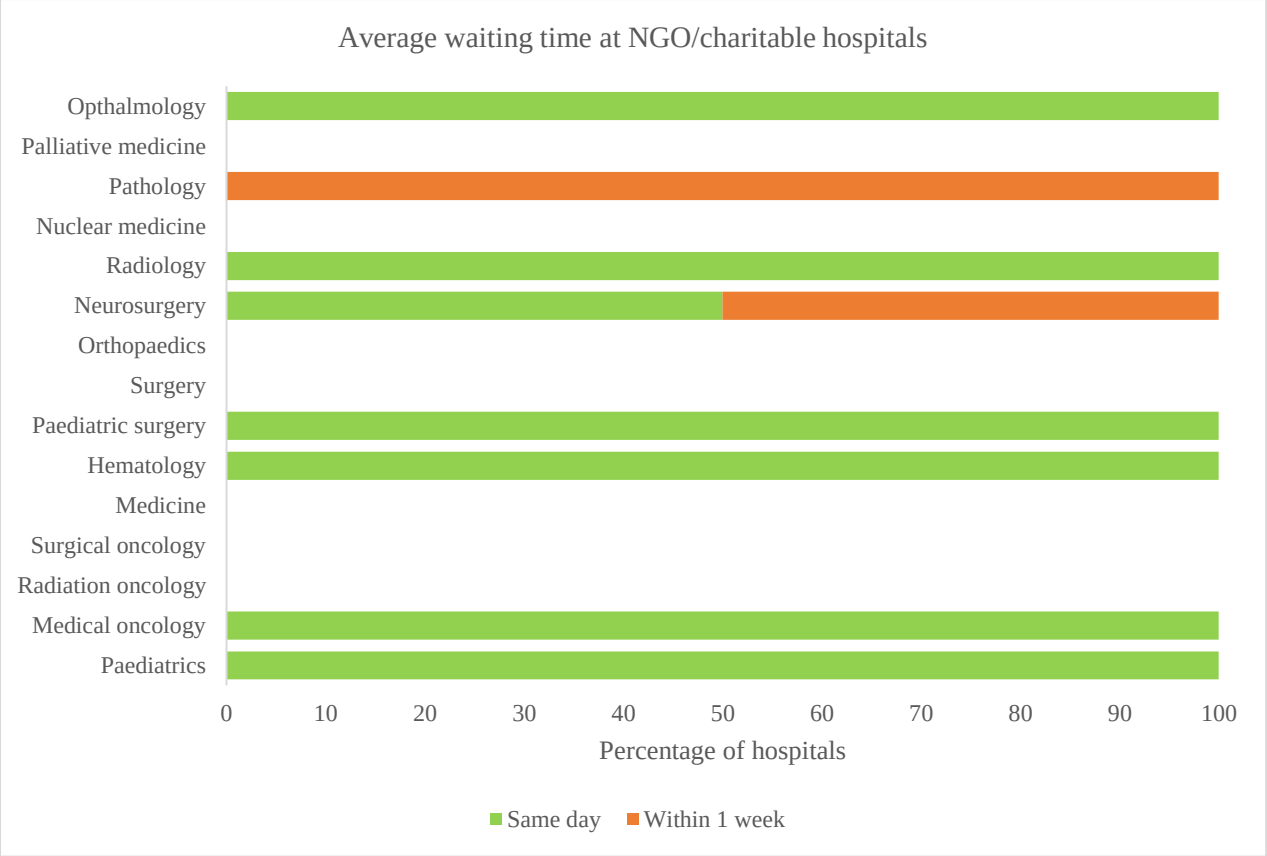
Average waiting time at NGO/charitable hospitals
Opthalmology
Palliative medicine
Pathology
Nuclear medicine
Radiology
Neurosurgery
Orthopaedics
Surgery
Paediatric surgery
Hematology
Medicine
Surgical oncology
Radiation oncology
Medical oncology
Paediatrics
0
10
20
30
40
50
60
70
80
90
100
Percentage of hospitals
Same day
Within 1 week

Fig. 41

7. Average waiting time for getting an appointment for laboratory services at tertiary hospitals

Table 18: Average waiting time for lab services at public tertiary hospitals

Investigation	Same day		Within one week		Within 2 weeks		Beyond 2 weeks	
	n	%	n	%	n	%	n	%
Histopathology	20	27.3	40	54.7	12	16.4	1	6.0
Immunohistochemistry	12	26.6	24	53.3	8	17.7	1	5.6
Flowcytometric Immunophenotyping	8	30.7	15	57.6	3	11.5		0
Cytogenetics	-	-	-	-	3	20	8	40
Tumour markers	15	31.2	24	50	7	14.5	2	13.7
Fluorescence in situ hybridization (FISH)	2	13.3	9	60	2	13.3	2	15
RT-PCR testing	18	40	21	46.6	5	11.1	1	9
HLA typing	2	16.6	6	50	2	16.6	2	12
Therapeutic drug monitoring	8	38.0	12	57.1	1	4.7		0

Table 19: Average waiting time for lab services at Private tertiary hospitals

Investigation	Same day		Within one week		Within two weeks		Beyond 2 weeks	
	n	%	n	%	n	%	n	%
Histopathology	16	50.0	14	43.7	2	6.2	-	-
Immunohistochemistry	11	44.0	11	44.0	2	8.0	1	4.0
Flowcytometric Immunophenotyping	13	61.9	8	38.0	-	-	-	0
Cytogenetics	-	-	-	-	-		1	8.3
Tumour markers	18	62.0	10	34.4	1	3.4	-	-
Fluorescence in situ hybridization (FISH)	3	30.0	7	70.0	-	-	-	-
RT-PCR testing	11	61.1	7	38.8	-	-	-	-
HLA typing	3	37.5	3	37.5	2	25.0	-	-
Therapeutic drug monitoring	8	72.7	3	27.2	-	-	-	-

Table 20: Average waiting time for lab services at NGO/charitable tertiary hospitals

Investigation	Same day		Within one week		Within 2 weeks		Beyond 2 weeks	
	n	%	n	%	n	%	n	%
Histopathology	10	47.6	10	47.6	1	4.7	0	0
Immunohistochemistry	8	47.0	6	35.2	3	17.6	0	0
Flowcytometric Immunophenotyping	6	60	4	40	0	0		0
Cytogenetics	0	0	2	25	0	0	2	25
Tumour markers	13	68.4	5	26.3	1	5.2	0	0
Fluorescence in situ hybridization (FISH)	3	42.8	3	42.8	1	14.2	0	0
RT-PCR testing	10	71.4	3	21.4	1	7.1	0	0
HLA typing	2	40	1	20	2	40	0	0
Therapeutic drug monitoring	5	62.5	2	25	1	12.5		0

8. Availability and referral services for laboratory services were not available at the tertiary hospitals

Table 21: Availability and mode of referral services for laboratory services that are not available at the public tertiary hospital

Investigation	Patients' referral when the investigation is unavailable at the tertiary public hospital								
		Pvt lab		Govt hospital		Other		Not referred	
	N	n	%	n	%	n	%	n	%
Histopathology	**4**	1	25	2	50.0	1	25.0	0	0
Immunohistochemistry	**32**	15	46.8	9	28.1	3	9.3	4	12.5
Flowcytometric Immunophenotyping	**51**	22	43.1	18	35.2	2	3.9	9	17.6
Cytogenetics	**62**	30	48.3	21	33.8	3	4.8	4	6.4
Tumour markers	**29**	12	41.3	11	37.9	1	3.4	5	17.2
HLA typing	**65**	31	47.6	21	32.3	3	4.6	10	15.3
Therapeutic drug monitoring	**56**	23	41.0	14	25.0	4	7.1	15	26.7

Table 22: Availability and mode of referral services for laboratory services that are not available at the private tertiary hospital

Investigation	Patients' referral when the investigation is unavailable at the tertiary Private hospital								
	N	Pvt lab		Govt hospital		other		Not referred	
		n	%	n	%	n	%	n	%
Histopathology	**3**	2	66.6	1	33.3	0	0		0
Immunohistochemistry	**10**	6	60.0	3	30	1	10	0	0
Flowcytometric Immunophenotyping	**14**	9	64.2	3	21.4	1	7.1	1	7.1
Cytogenetics	**23**	20	86.9	2	8.6	0	0	1	4.3
Tumour markers	**6**	5	83.3	1	16.6		0		0
HLA typing	**27**	22	81.4	4	14.8	0	0	1	3.7
Therapeutic drug monitoring	**24**	12	50	4	16.6	1	4.1	6	25

Table 23: Availability and mode of referral services for laboratory services that are not available at NGO/Charitable hospital

Investigation	Patients' referral when the investigation is unavailable at the tertiary NGO/Charitable hospital								
	N	Pvt lab		Govt hospital		Other		Not referred	
		n	%	n	%	n	%	n	%
Histopathology	**4**	3	75	0	0	1	25	0	0
Immunohistochemistry	**8**	5	62.5	1	12.5	1	12.5	0	0
Flowcytometric Immunophenotyping	**15**	11	73.3	2	13.3	1	6.6	1	6.6
Cytogenetics	**17**	13	76.4	2	11.7	0	0	2	11.7
Tumour markers	**6**	4	66.6	1	16.6	0	0	0	0
HLA typing	**20**	15	75	2	10	0	0	3	15
Therapeutic drug monitoring	**17**	10	58.8	3	17.6	0	0	4	23.5

9. Average waiting time for radiologic and nuclear medicine services at tertiary hospitals

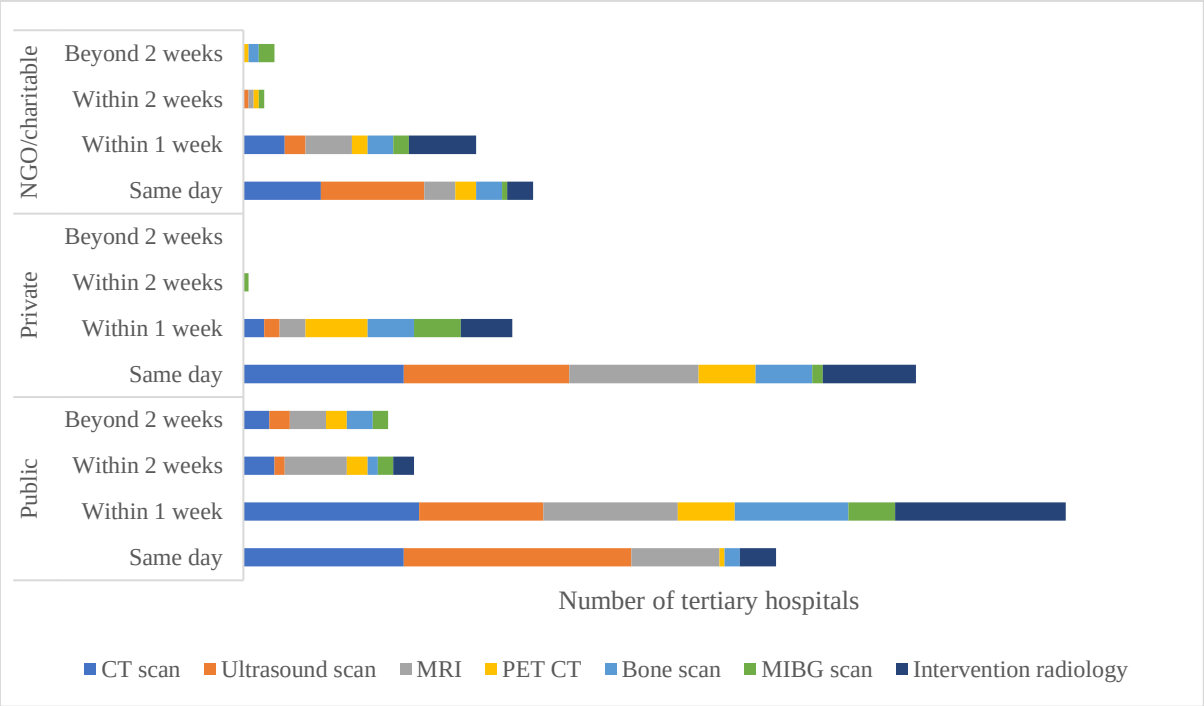

Fig. 42

10. Availability and mode of referral services for radiologic and nuclear services that are not available at the tertiary hospital

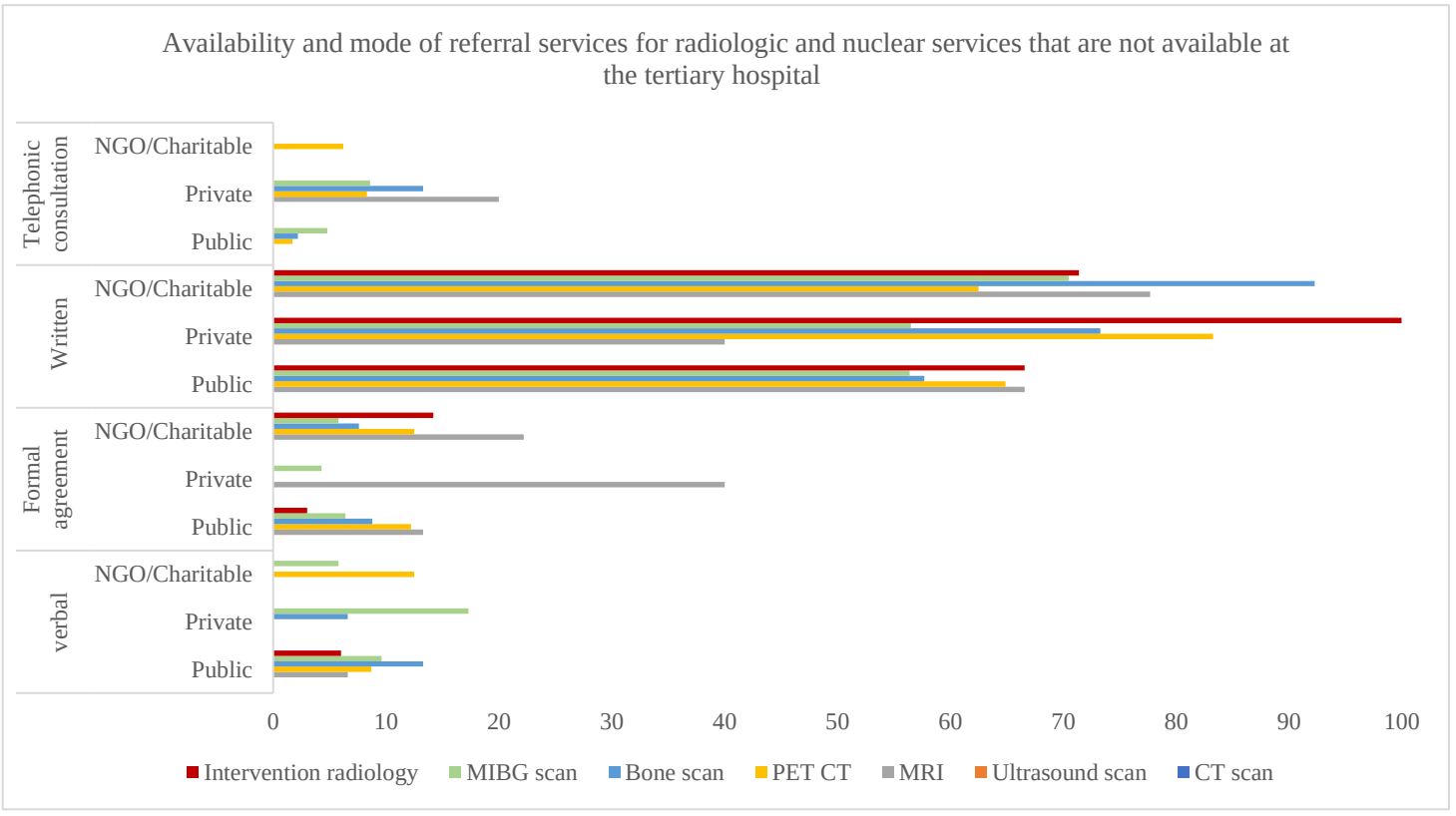

Fig. 43

11.Average waiting time for diagnostic services at secondary level hospitals

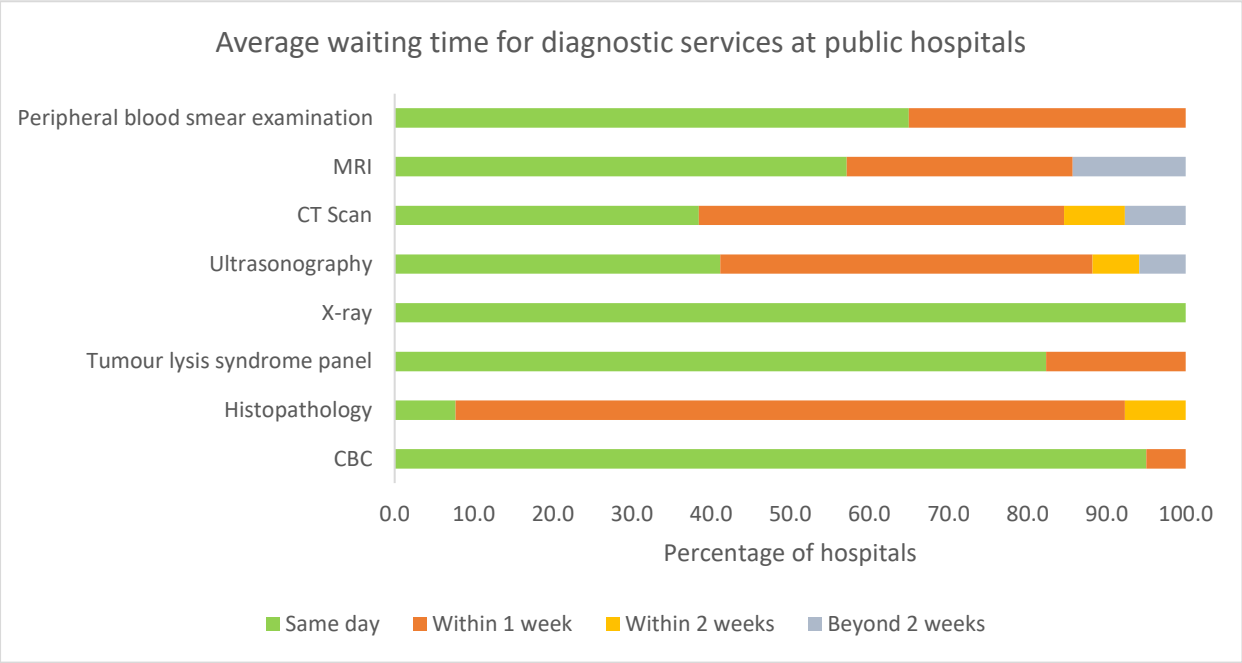

Fig. 44

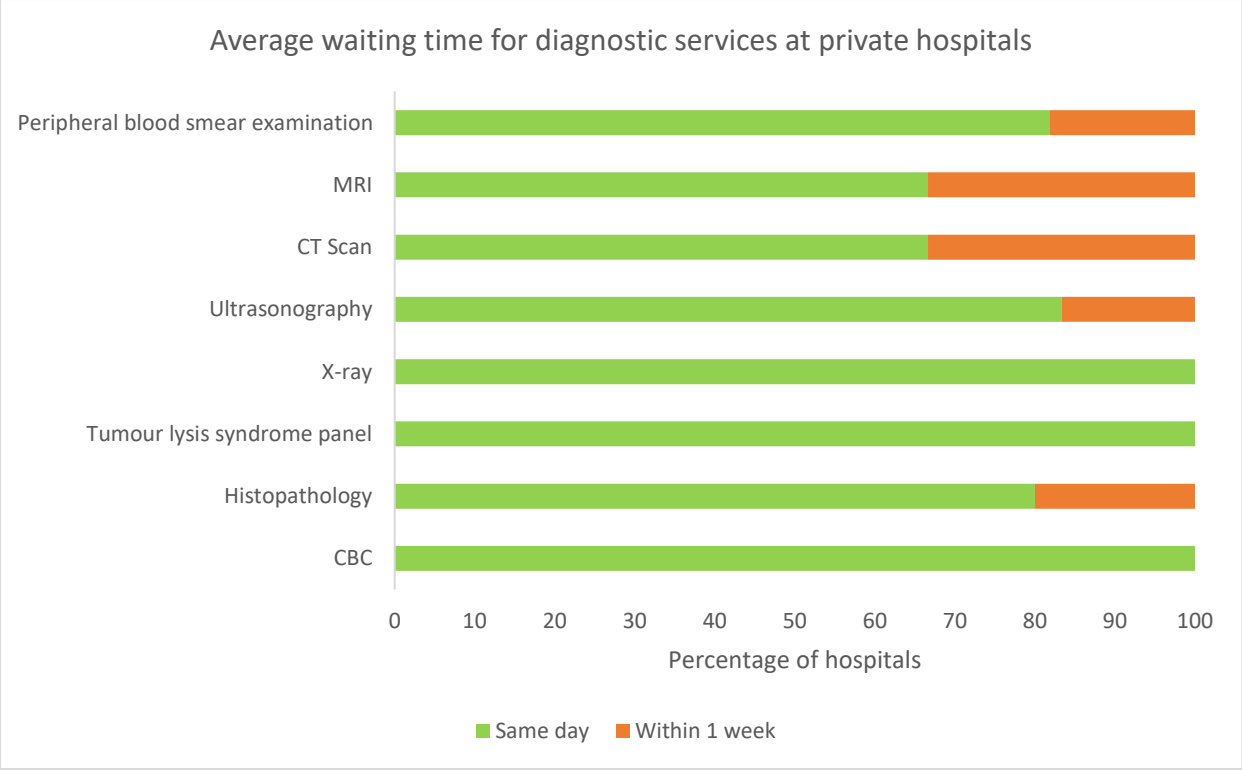

Fig. 45

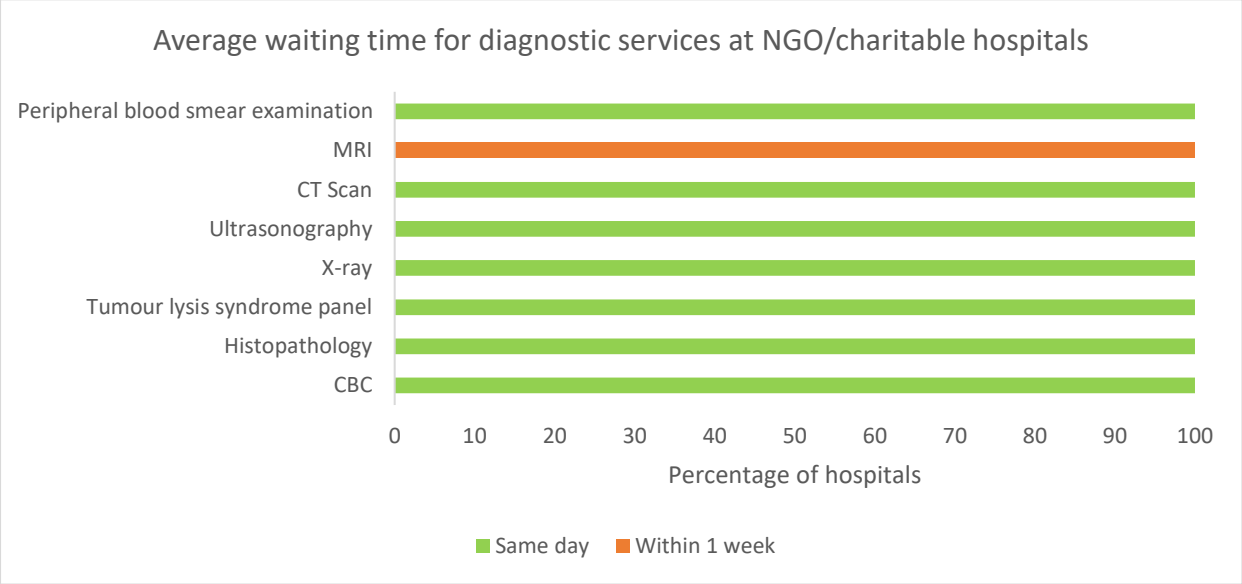

Fig. 46

12. Average waiting time to avail of specified treatment procedures at tertiary hospitals

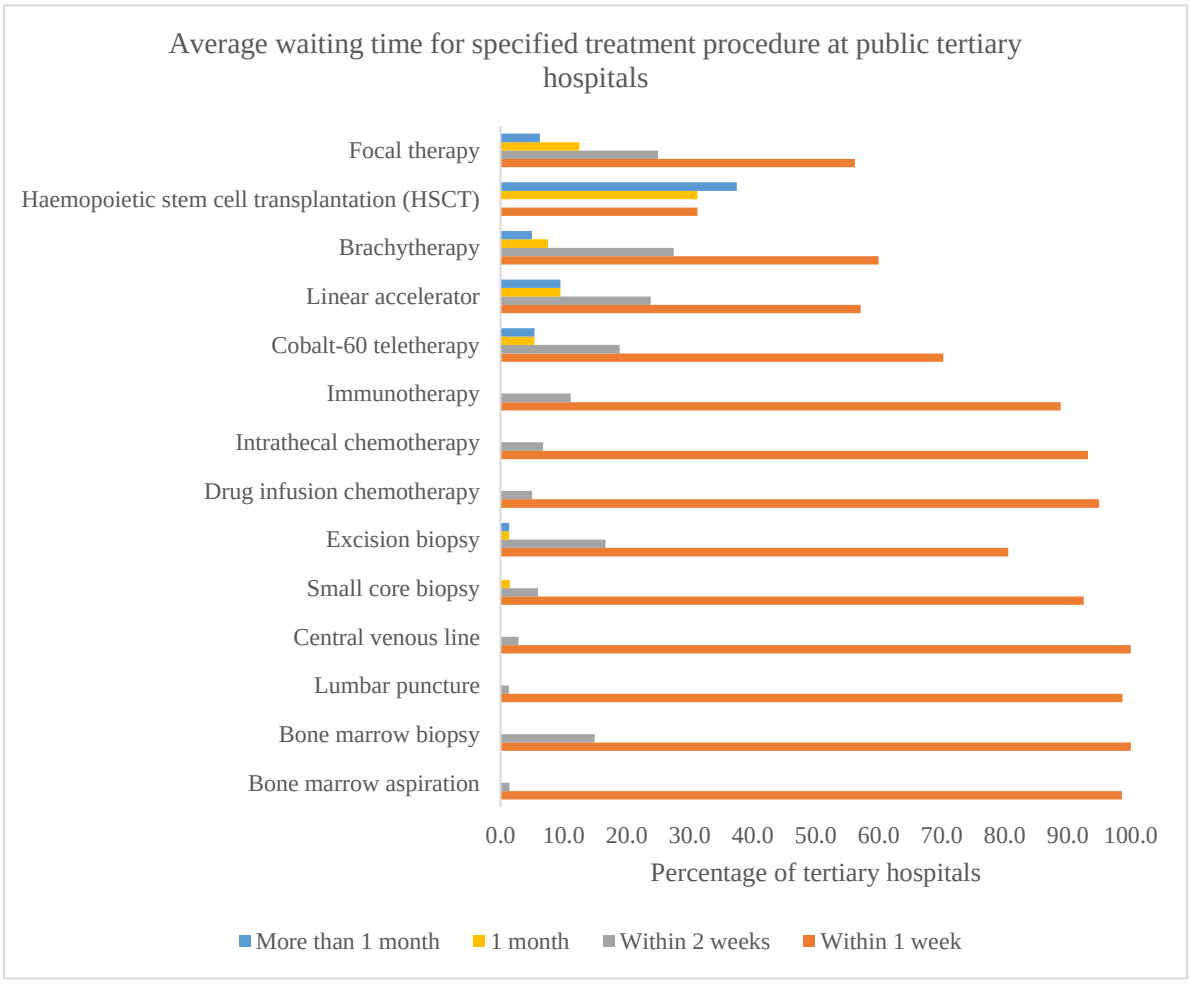

Fig. 47

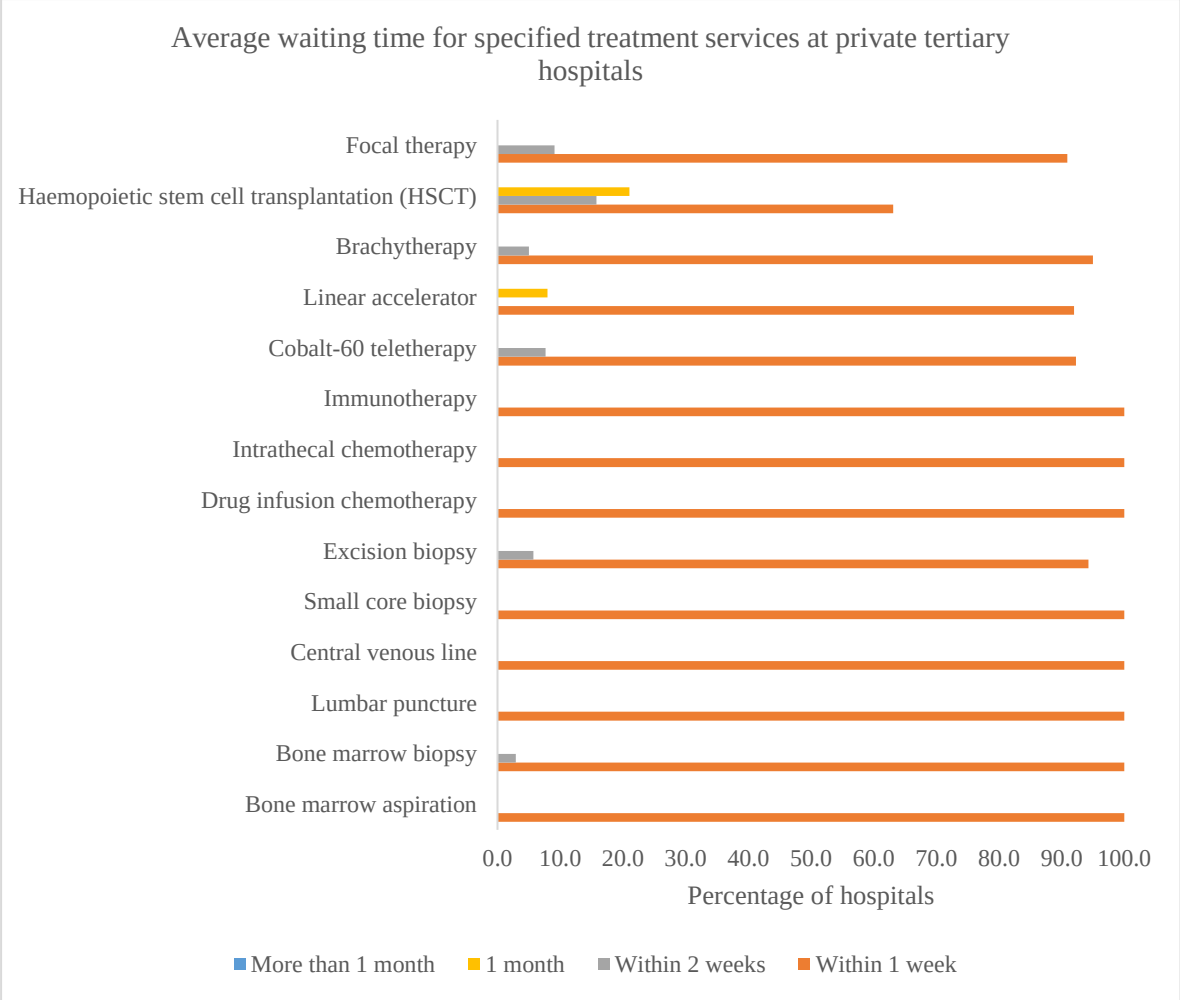
Average waiting time for specified treatment services at private tertiary hospitals
Focal therapy
Haemopoietic stem cell transplantation (HSCT)
Brachytherapy
Linear accelerator
Cobalt-60 teletherapy
Immunotherapy
Intrathecal chemotherapy
Drug infusion chemotherapy
Excision biopsy
Small core biopsy
Central venous line
Lumbar puncture
Bone marrow biopsy
Bone marrow aspiration
0.0 10.0 20.0 30.0 40.0 50.0 60.0 70.0 80.0 90.0 100.0
Percentage of hospitals
More than 1 month
1 month
Within 2 weeks
Within 1 week

Fig. 48

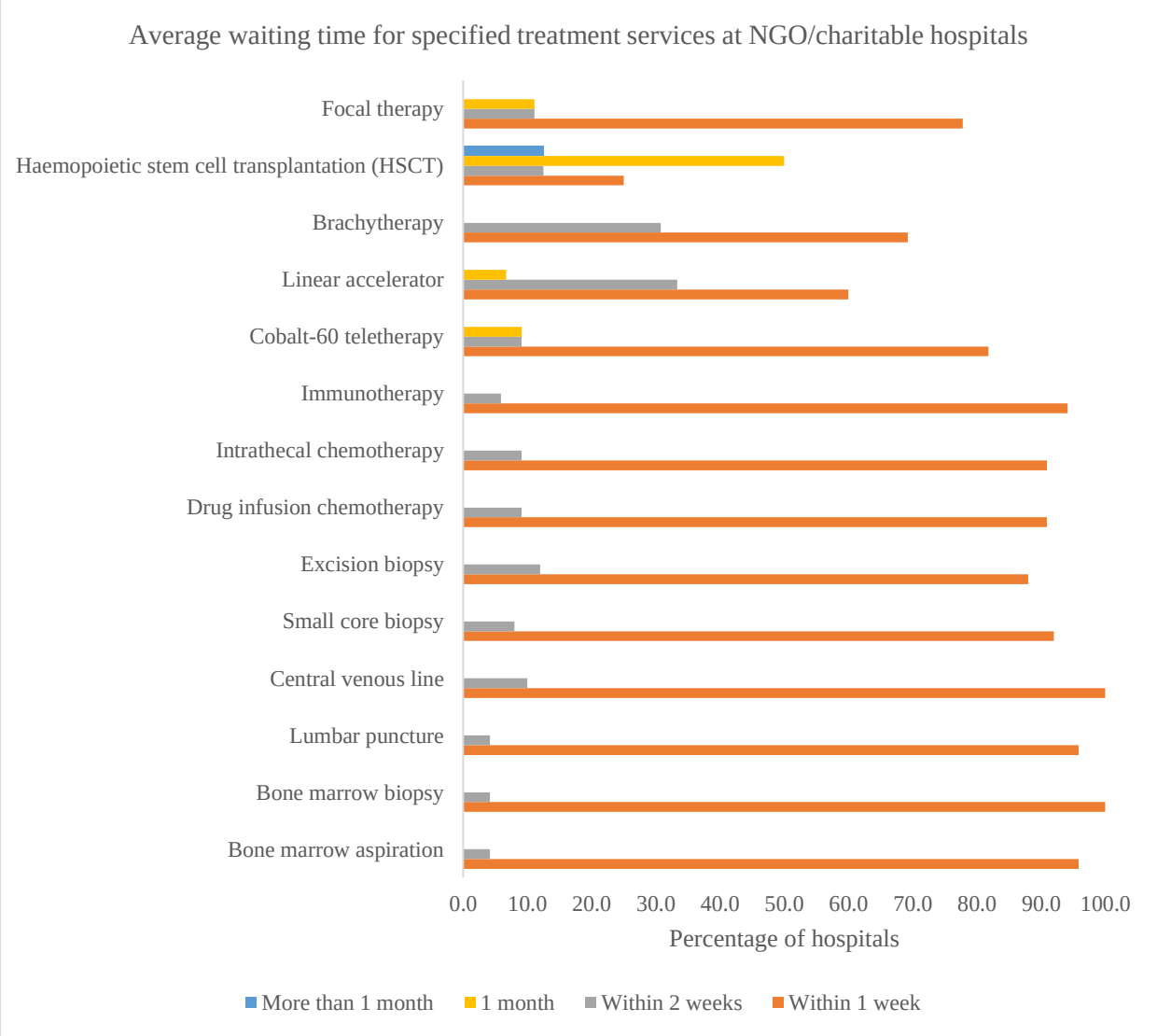
Average waiting time for specified treatment services at NGO/charitable hospitals
Focal therapy
Haemopoietic stem cell transplantation (HSCT)
Brachytherapy
Linear accelerator
Cobalt-60 teletherapy
Immunotherapy
Intrathecal chemotherapy
Drug infusion chemotherapy
Excision biopsy
Small core biopsy
Central venous line
Lumbar puncture
Bone marrow biopsy
Bone marrow aspiration
0.0 10.0 20.0 30.0 40.0 50.0 60.0 70.0 80.0 90.0 100.0
Percentage of hospitals
More than 1 month
1 month
Within 2 weeks
Within 1 week

Fig. 49

13.Means for seeking consultation from specialists not available in the tertiary hospital

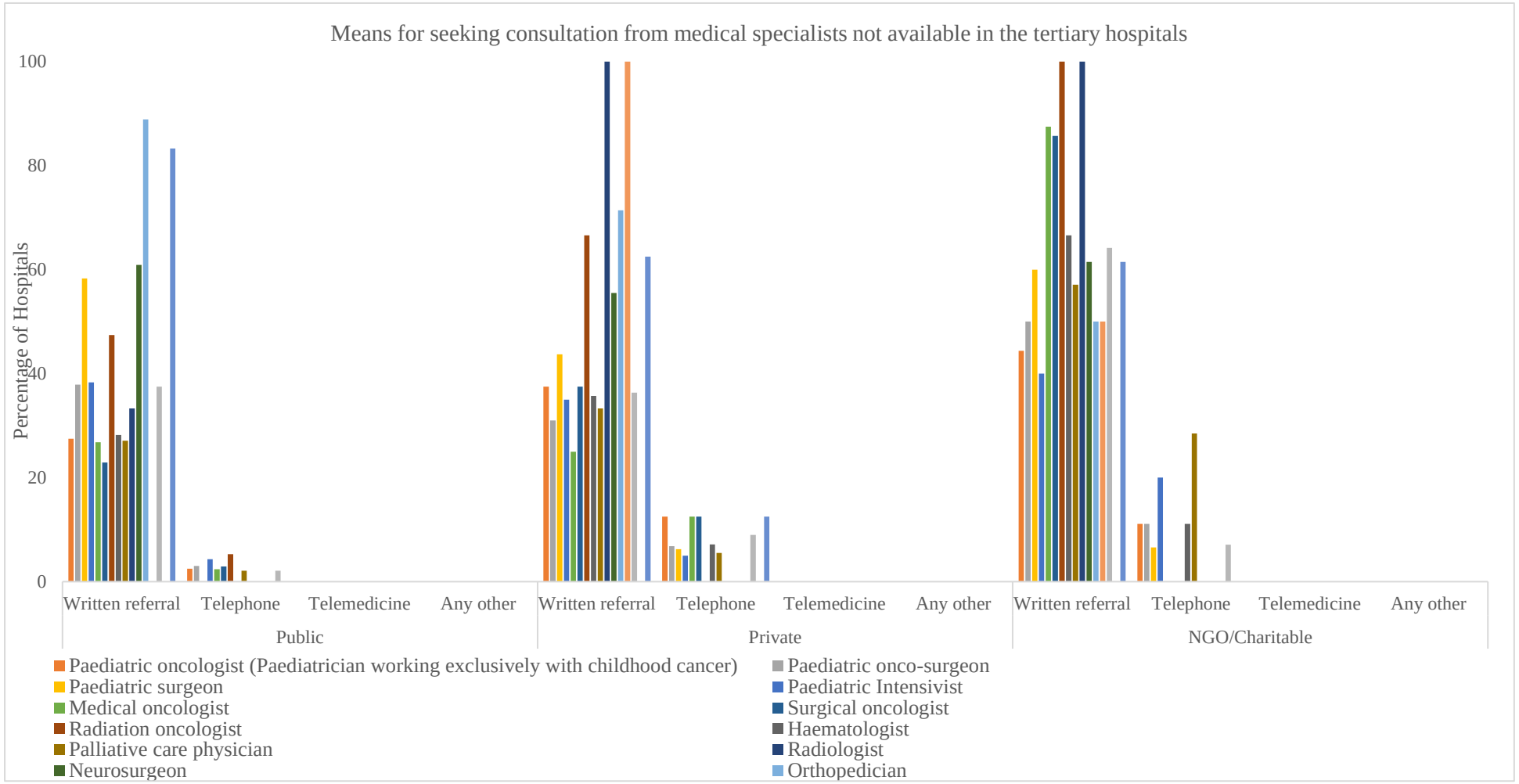

Fig. 50

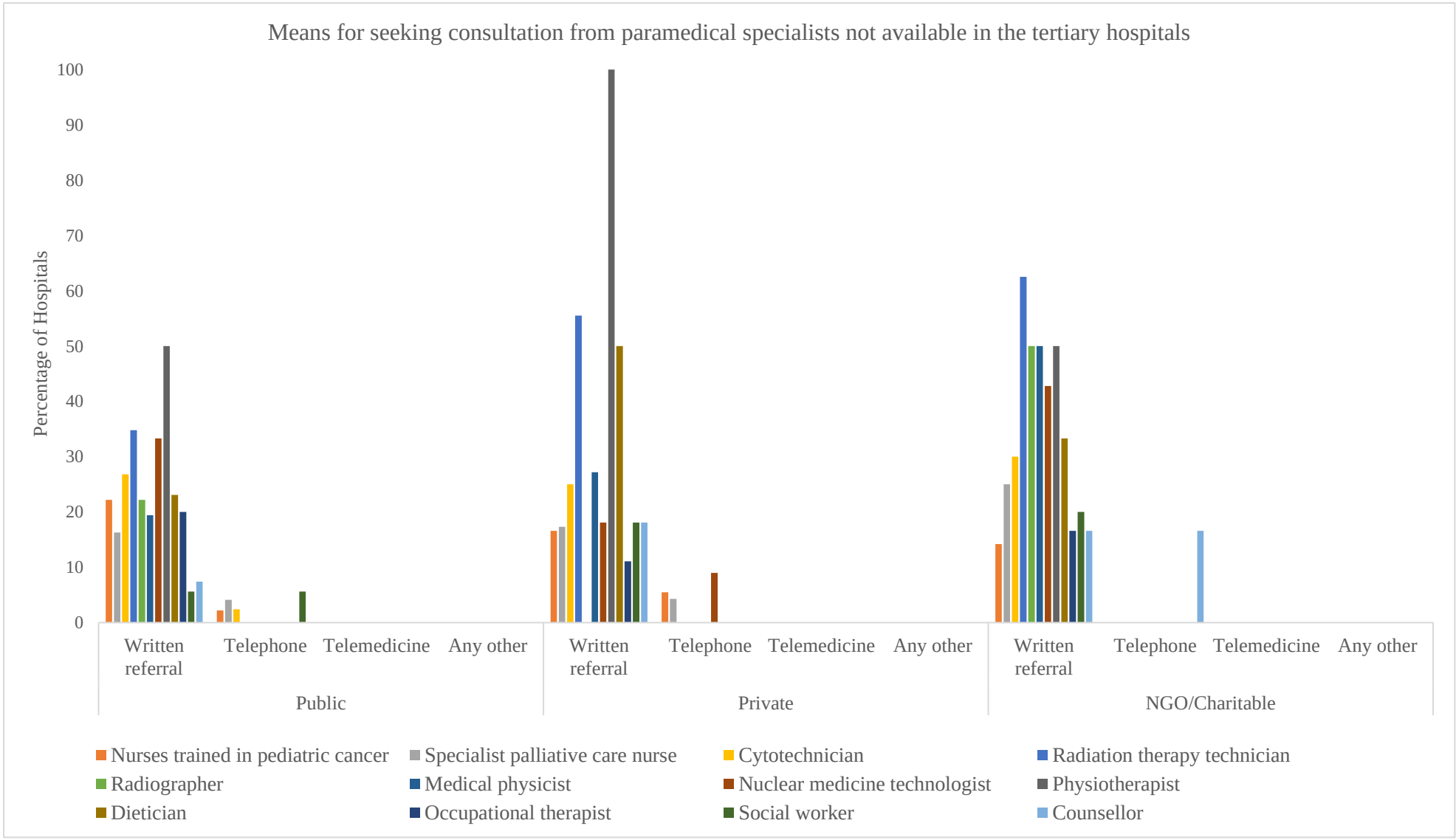
Means for seeking consultation from paramedical specialists not available in the tertiary hospitals
Percentage of Hospitals
100
90
80
70
60
50
40
30
20
10
0
Written referral
Telephone
Telemedicine
Any other
Public
Private
NGO/Charitable
Nurses trained in pediatric cancer
Specialist palliative care nurse
Cytotechnician
Radiation therapy technician
Radiographer
Medical physicist
Nuclear medicine technologist
Physiotherapist
Dietician
Occupational therapist
Social worker
Counsellor

Figure 51

14.Drugs for palliative care

14.1 Availability and costing of drugs used in palliative care in public tertiary hospitals

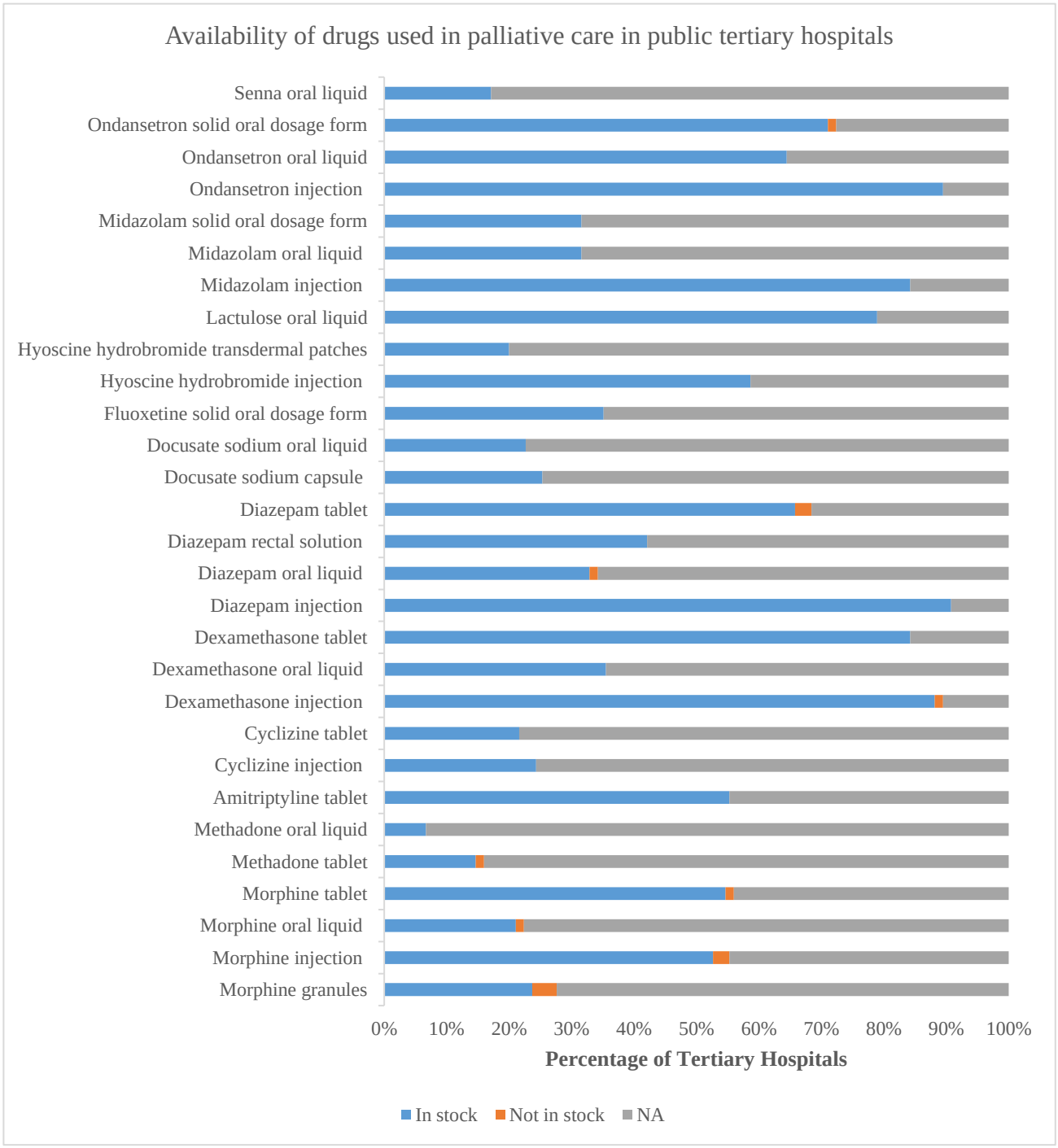

Fig. 52

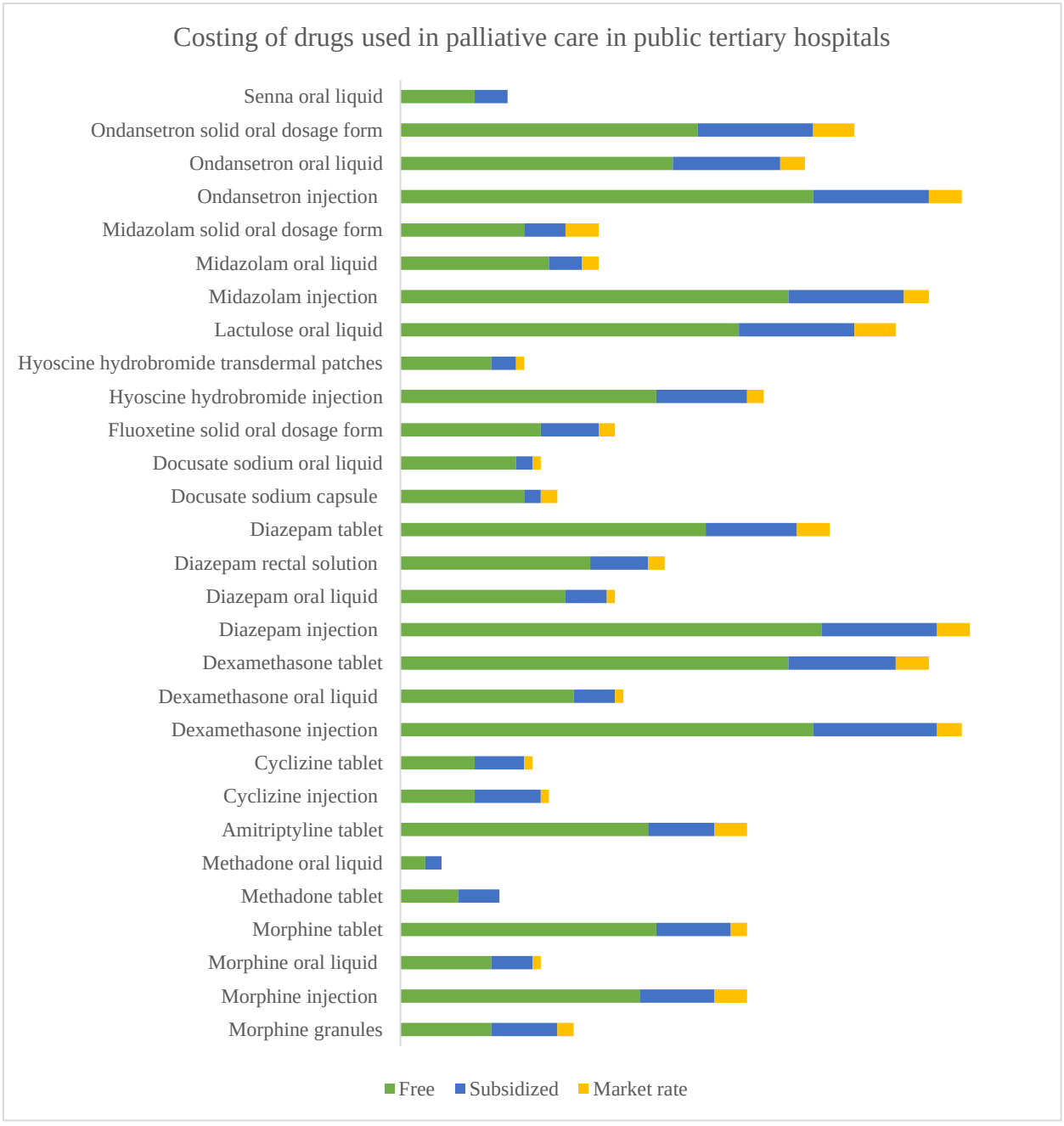
Costing of drugs used in palliative care in public tertiary hospitals
Senna oral liquid
Ondansetron solid oral dosage form
Ondansetron oral liquid
Ondansetron injection
Midazolam solid oral dosage form
Midazolam oral liquid
Midazolam injection
Lactulose oral liquid
Hyoscine hydrobromide transdermal patches
Hyoscine hydrobromide injection
Fluoxetine solid oral dosage form
Docusate sodium oral liquid
Docusate sodium capsule
Diazepam tablet
Diazepam rectal solution
Diazepam oral liquid
Diazepam injection
Dexamethasone tablet
Dexamethasone oral liquid
Dexamethasone injection
Cyclizine tablet
Cyclizine injection
Amitriptyline tablet
Methadone oral liquid
Methadone tablet
Morphine tablet
Morphine oral liquid
Morphine injection
Morphine granules
Free
Subsidized
Market rate

Fig. 53

14.2 Availability and costing of drugs used for palliative care at private tertiary hospitals

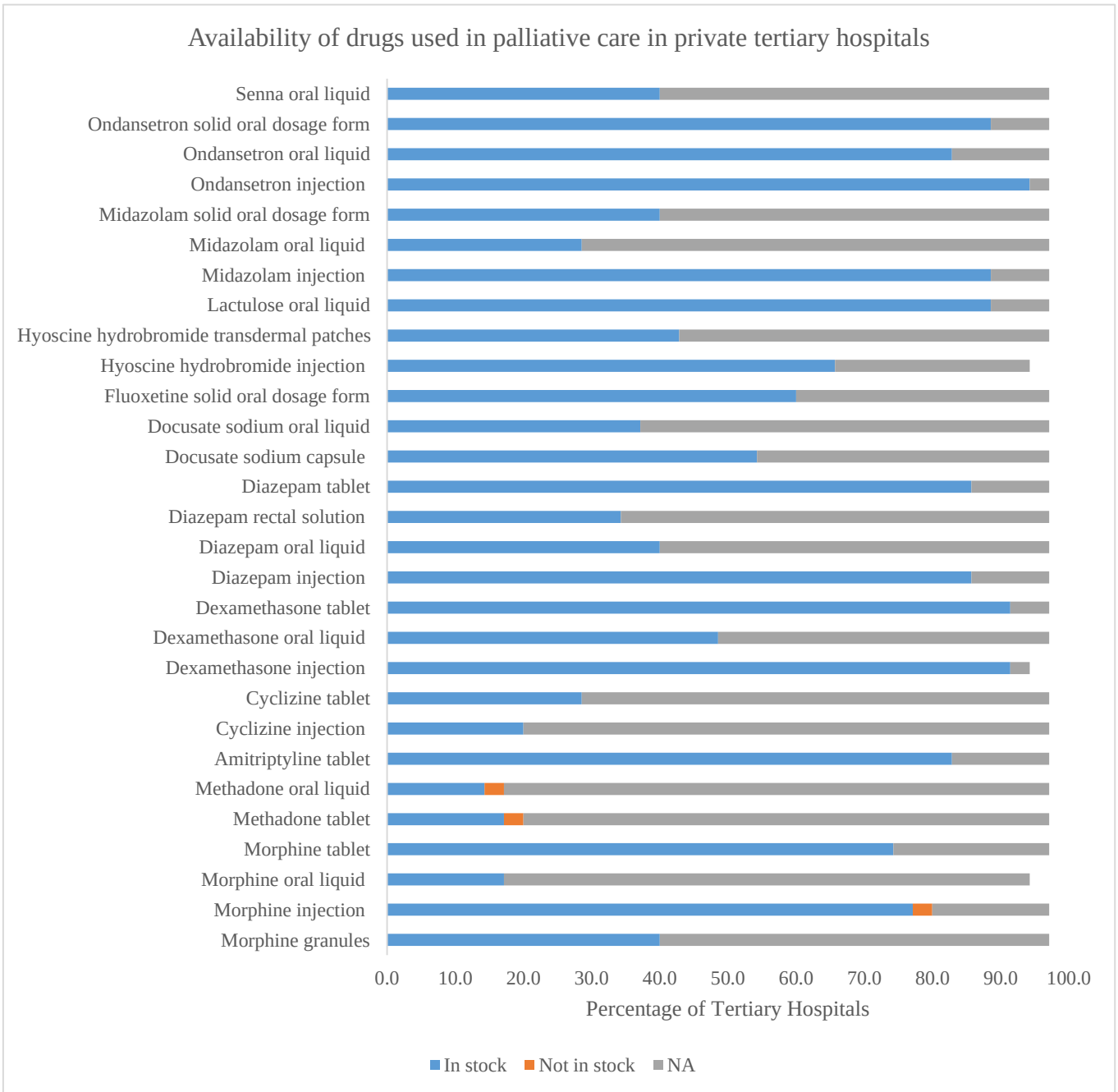

Fig. 54

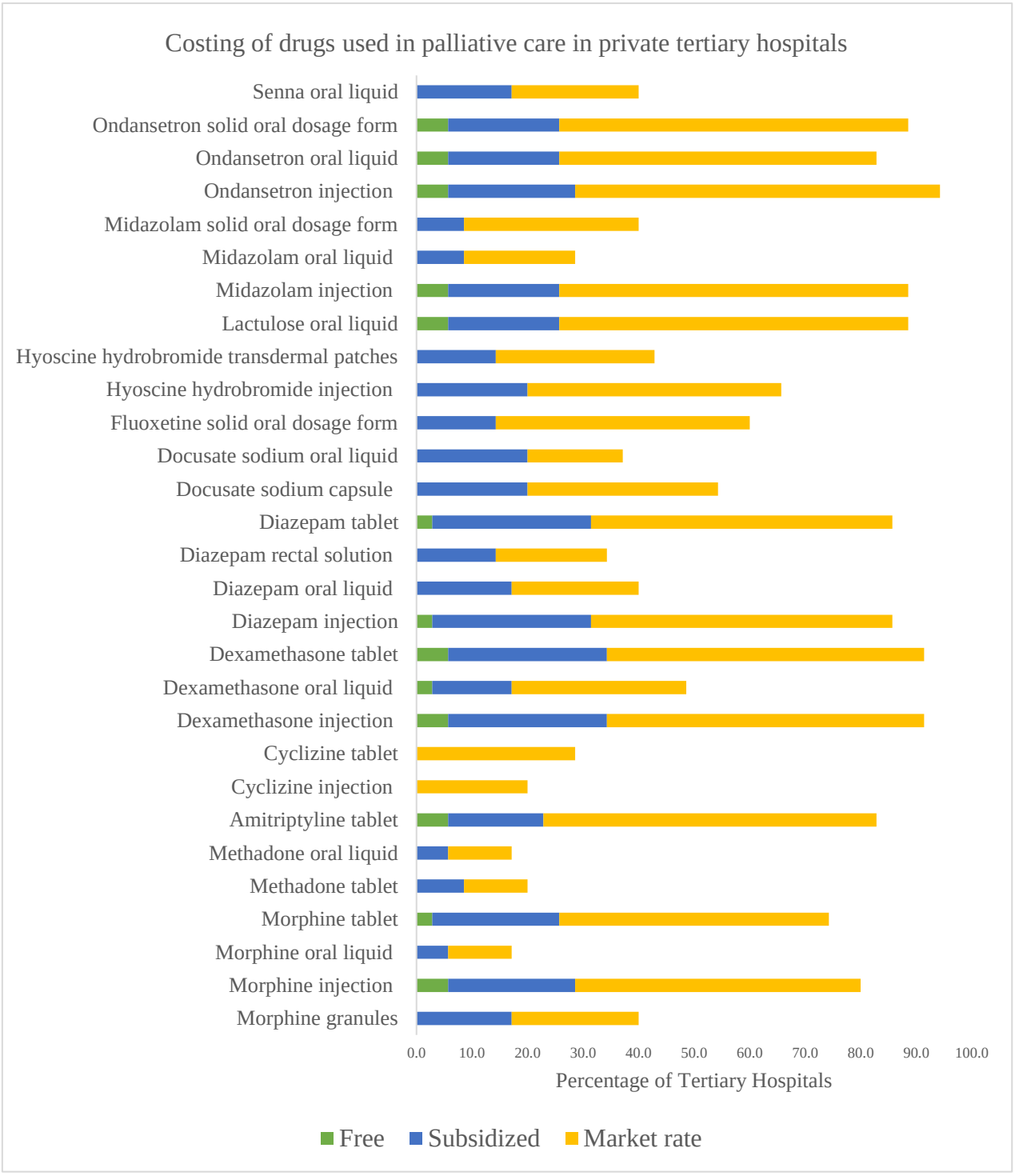
Costing of drugs used in palliative care in private tertiary hospitals
Senna oral liquid
Ondansetron solid oral dosage form
Ondansetron oral liquid
Ondansetron injection
Midazolam solid oral dosage form
Midazolam oral liquid
Midazolam injection
Lactulose oral liquid
Hyoscine hydrobromide transdermal patches
Hyoscine hydrobromide injection
Fluoxetine solid oral dosage form
Docusate sodium oral liquid
Docusate sodium capsule
Diazepam tablet
Diazepam rectal solution
Diazepam oral liquid
Diazepam injection
Dexamethasone tablet
Dexamethasone oral liquid
Dexamethasone injection
Cyclizine tablet
Cyclizine injection
Amitriptyline tablet
Methadone oral liquid
Methadone tablet
Morphine tablet
Morphine oral liquid
Morphine injection
Morphine granules
0.0
10.0
20.0
30.0
40.0
50.0
60.0
70.0
80.0
90.0
100.0
Percentage of Tertiary Hospitals
Free
Subsidized
Market rate

Fig. 55

14.3 Availability and costing of drugs used in palliative care in NGO/charitable tertiary hospitals

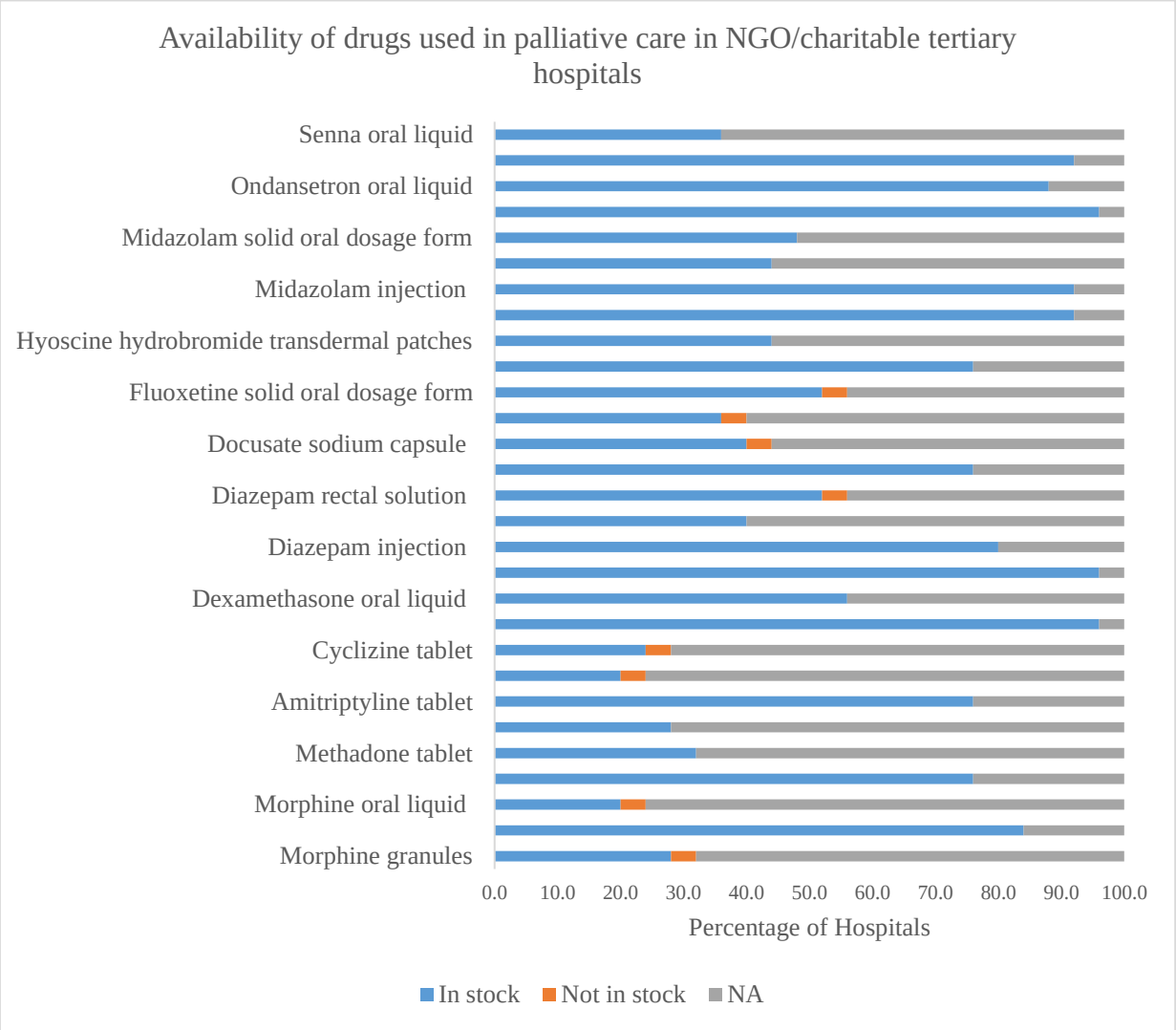

Fig. 56

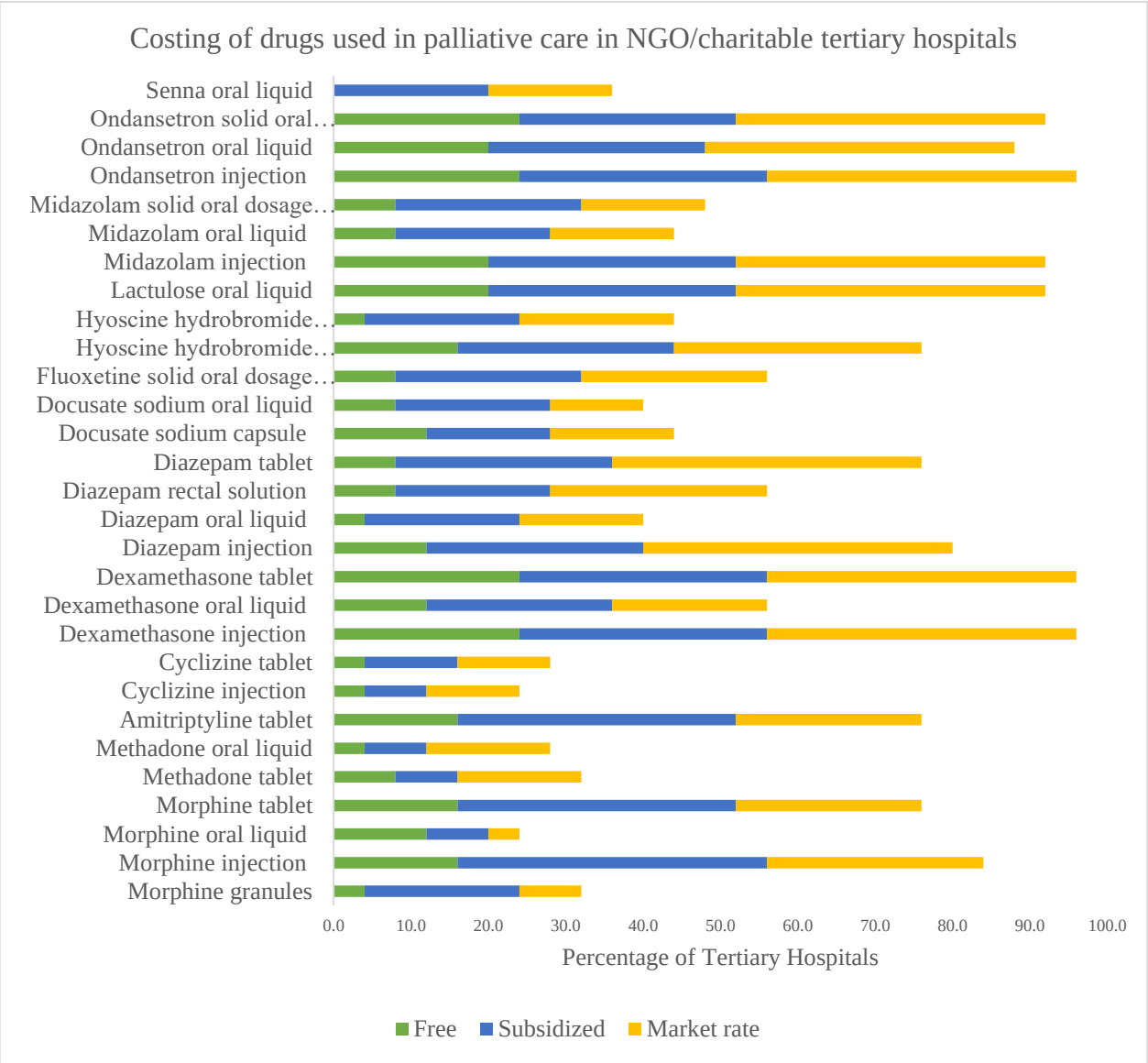
Costing of drugs used in palliative care in NGO/charitable tertiary hospitals
Senna oral liquid
Ondansetron solid oral…
Ondansetron oral liquid
Ondansetron injection
Midazolam solid oral dosage…
Midazolam oral liquid
Midazolam injection
Lactulose oral liquid
Hyoscine hydrobromide…
Hyoscine hydrobromide…
Fluoxetine solid oral dosage…
Docusate sodium oral liquid
Docusate sodium capsule
Diazepam tablet
Diazepam rectal solution
Diazepam oral liquid
Diazepam injection
Dexamethasone tablet
Dexamethasone oral liquid
Dexamethasone injection
Cyclizine tablet
Cyclizine injection
Amitriptyline tablet
Methadone oral liquid
Methadone tablet
Morphine tablet
Morphine oral liquid
Morphine injection
Morphine granules
0.0
10.0
20.0
30.0
40.0
50.0
60.0
70.0
80.0
90.0
100.0
Percentage of Tertiary Hospitals
Free
Subsidized
Market rate

Fig. 57

15.Targeted therapies

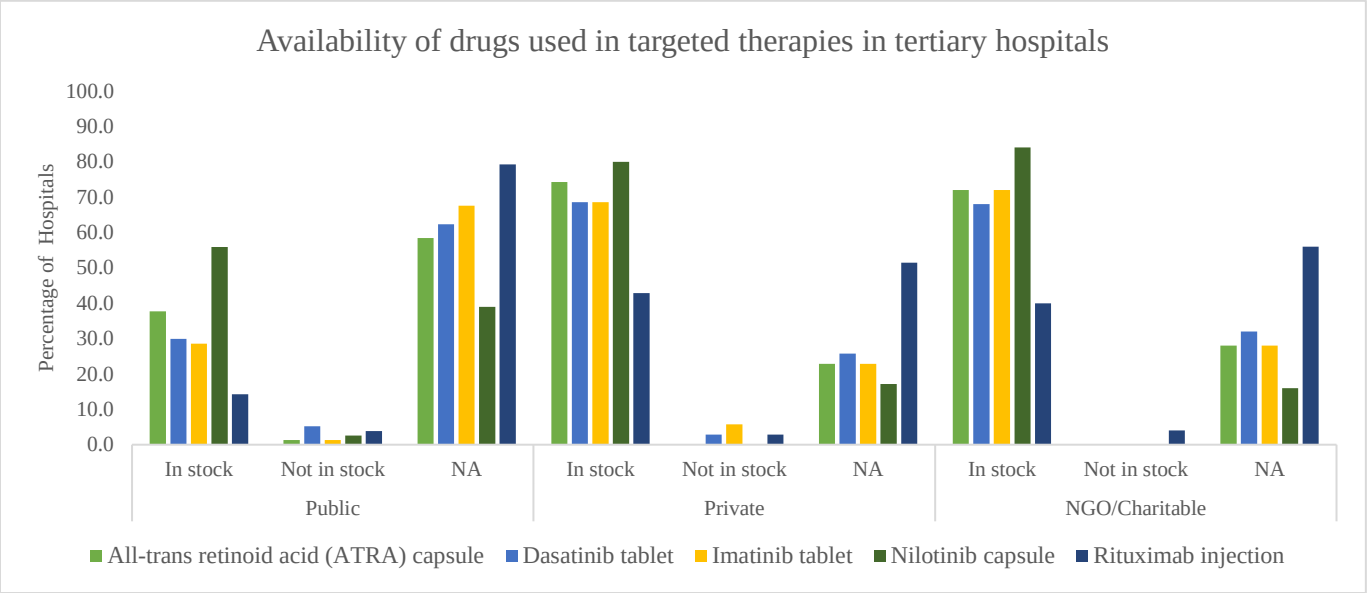

Fig. 58

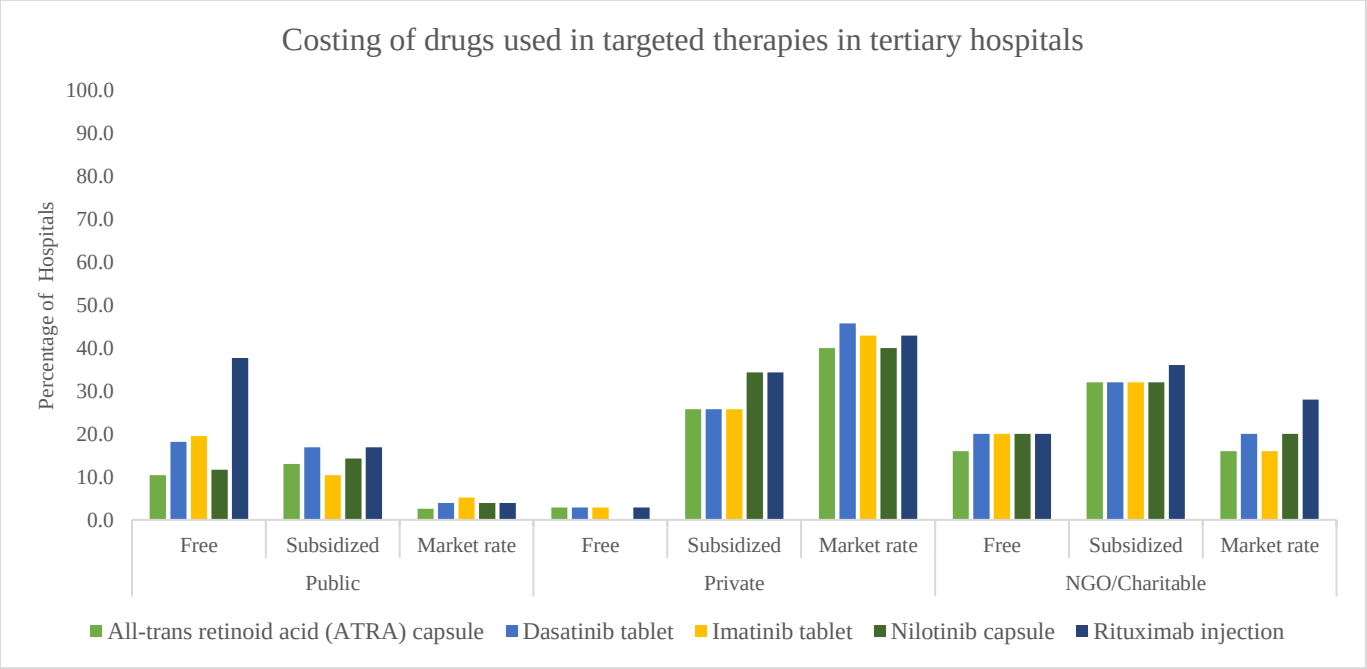

Fig. 59

16.Anti-neoplastic drugs

16.1 Availability and costing of antineoplastic drugs at public tertiary hospitals

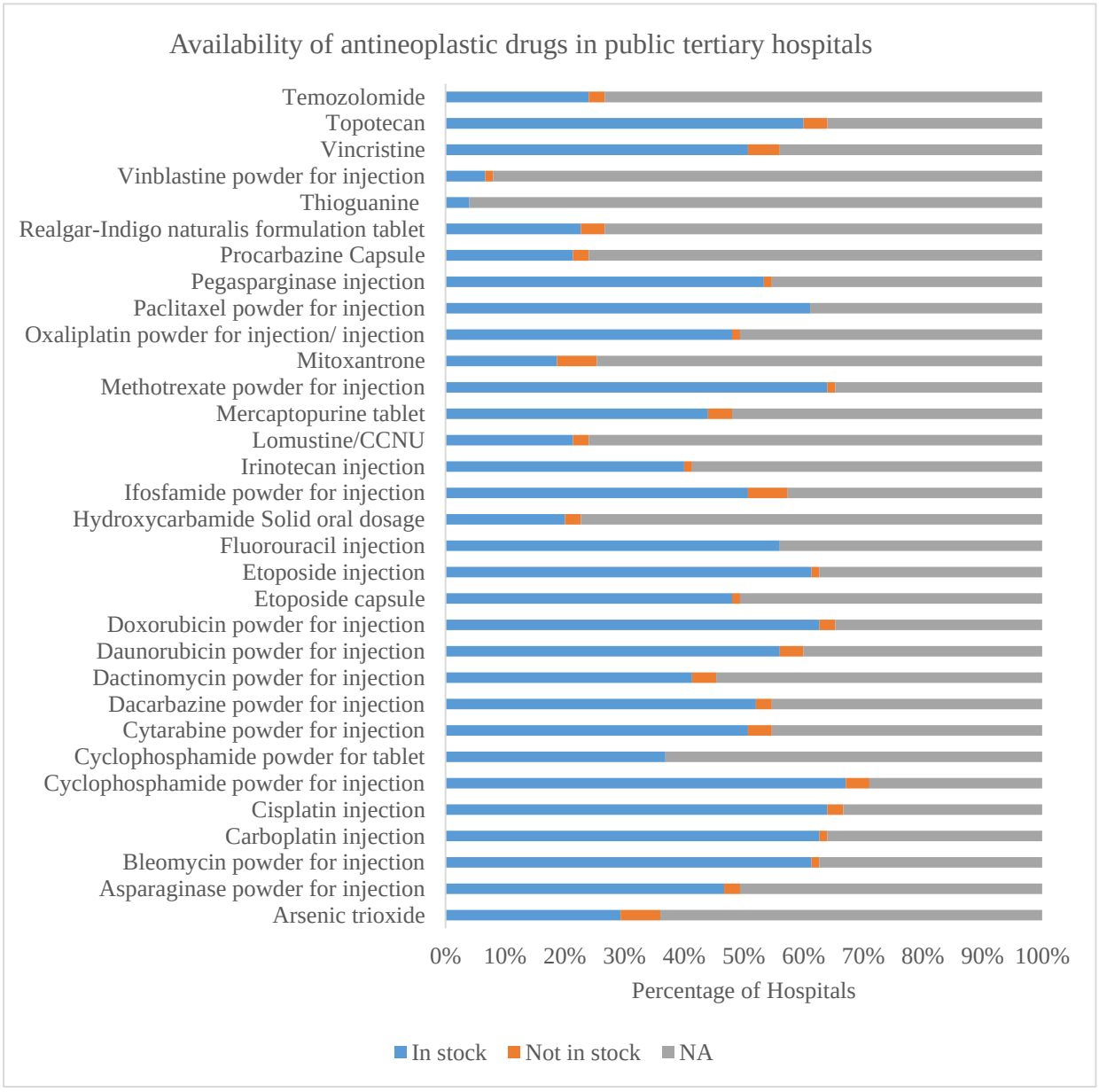

Fig. 60

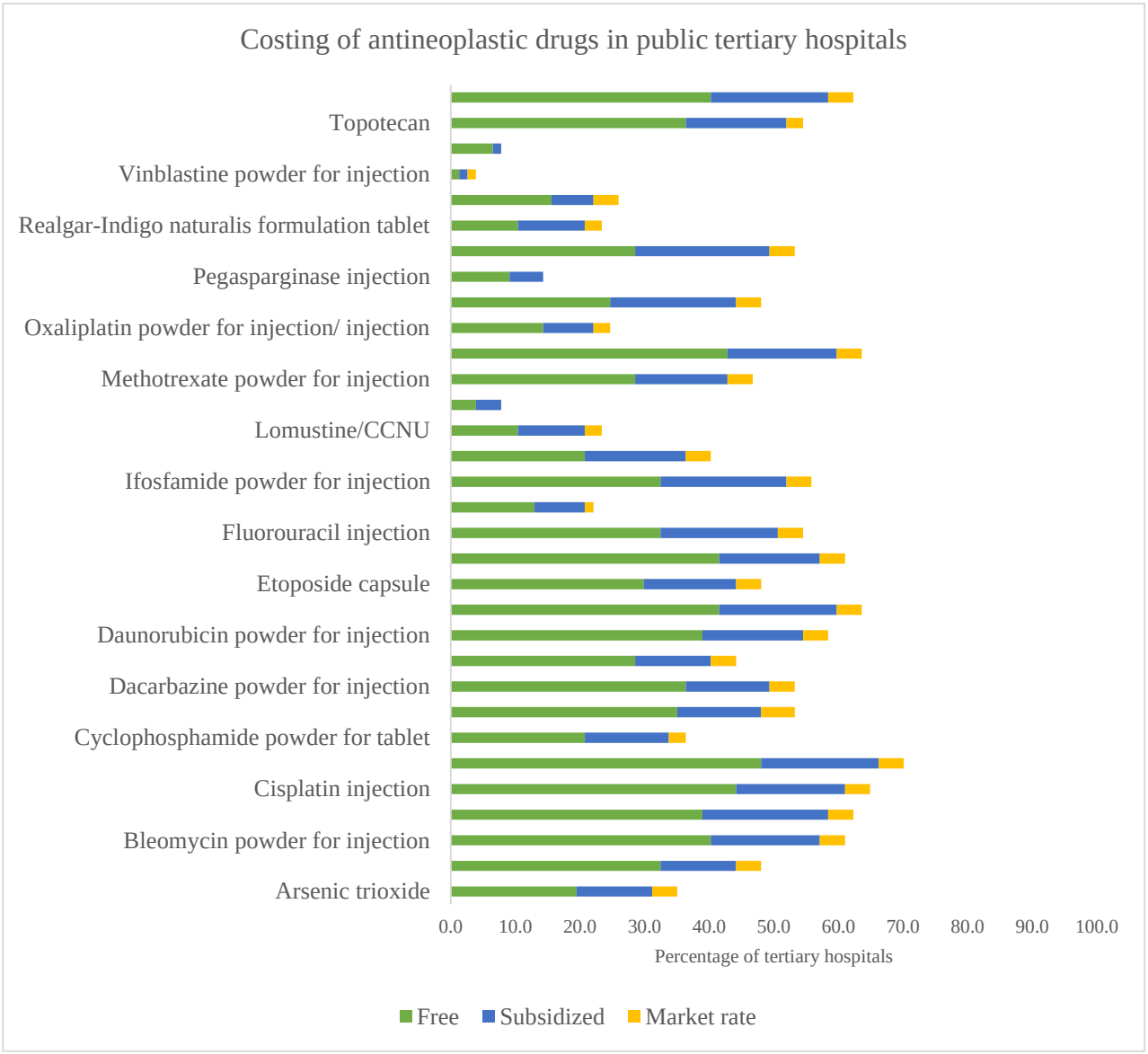
Costing of antineoplastic drugs in public tertiary hospitals
Topotecan
Vinblastine powder for injection
Realgar-Indigo naturalis formulation tablet
Pegasparginase injection
Oxaliplatin powder for injection/ injection
Methotrexate powder for injection
Lomustine/CCNU
Ifosfamide powder for injection
Fluorouracil injection
Etoposide capsule
Daunorubicin powder for injection
Dacarbazine powder for injection
Cyclophosphamide powder for tablet
Cisplatin injection
Bleomycin powder for injection
Arsenic trioxide
0.0
10.0
20.0
30.0
40.0
50.0
60.0
70.0
80.0
90.0
100.0
Percentage of tertiary hospitals
Free
Subsidized
Market rate

Fig. 61

16.2 Availability of antineoplastic drugs at private tertiary hospitals

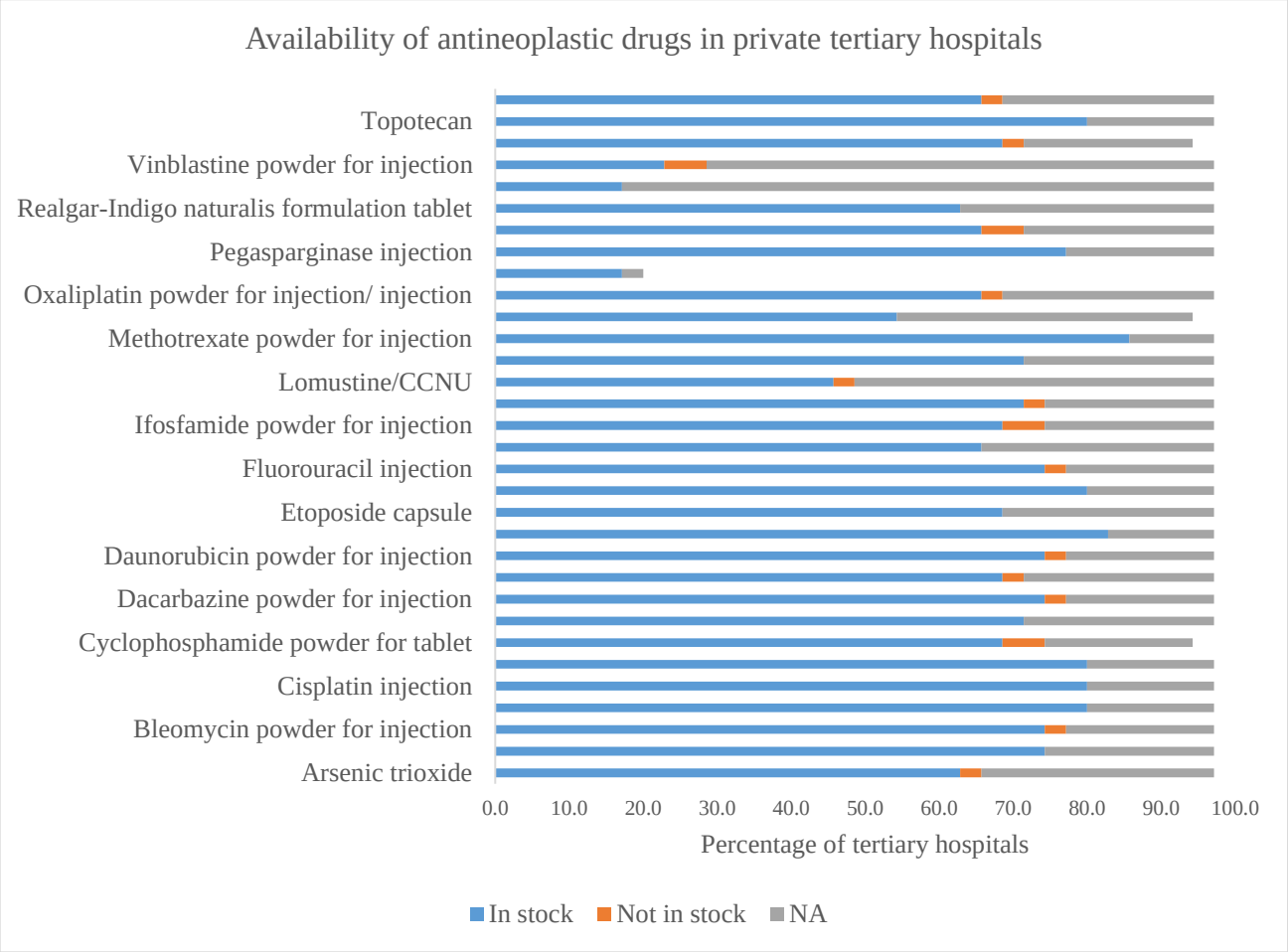

Fig. 62

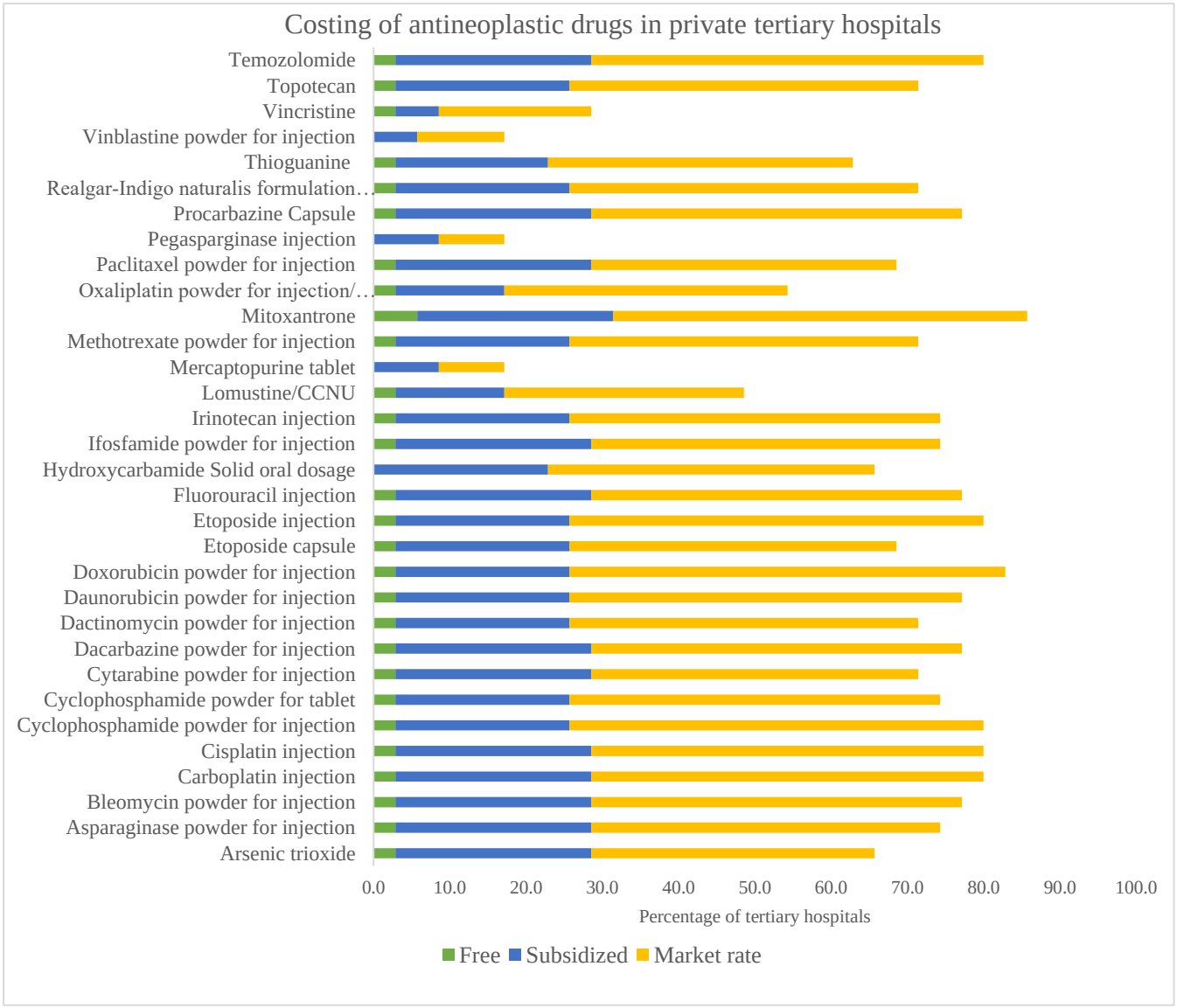
Costing of antineoplastic drugs in private tertiary hospitals
Temozolomide
Topotecan
Vincristine
Vinblastine powder for injection
Thioguanine
Realgar-Indigo naturalis formulation…
Procarbazine Capsule
Pegasparginase injection
Paclitaxel powder for injection
Oxaliplatin powder for injection/…
Mitoxantrone
Methotrexate powder for injection
Mercaptopurine tablet
Lomustine/CCNU
Irinotecan injection
Ifosfamide powder for injection
Hydroxycarbamide Solid oral dosage
Fluorouracil injection
Etoposide injection
Etoposide capsule
Doxorubicin powder for injection
Daunorubicin powder for injection
Dactinomycin powder for injection
Dacarbazine powder for injection
Cytarabine powder for injection
Cyclophosphamide powder for tablet
Cyclophosphamide powder for injection
Cisplatin injection
Carboplatin injection
Bleomycin powder for injection
Asparaginase powder for injection
Arsenic trioxide
0.0
10.0
20.0
30.0
40.0
50.0
60.0
70.0
80.0
90.0
100.0
Percentage of tertiary hospitals
Free
Subsidized
Market rate

Fig. 63

16.3 Availability and costing of antineoplastic drugs at NGO/charitable tertiary hospitals

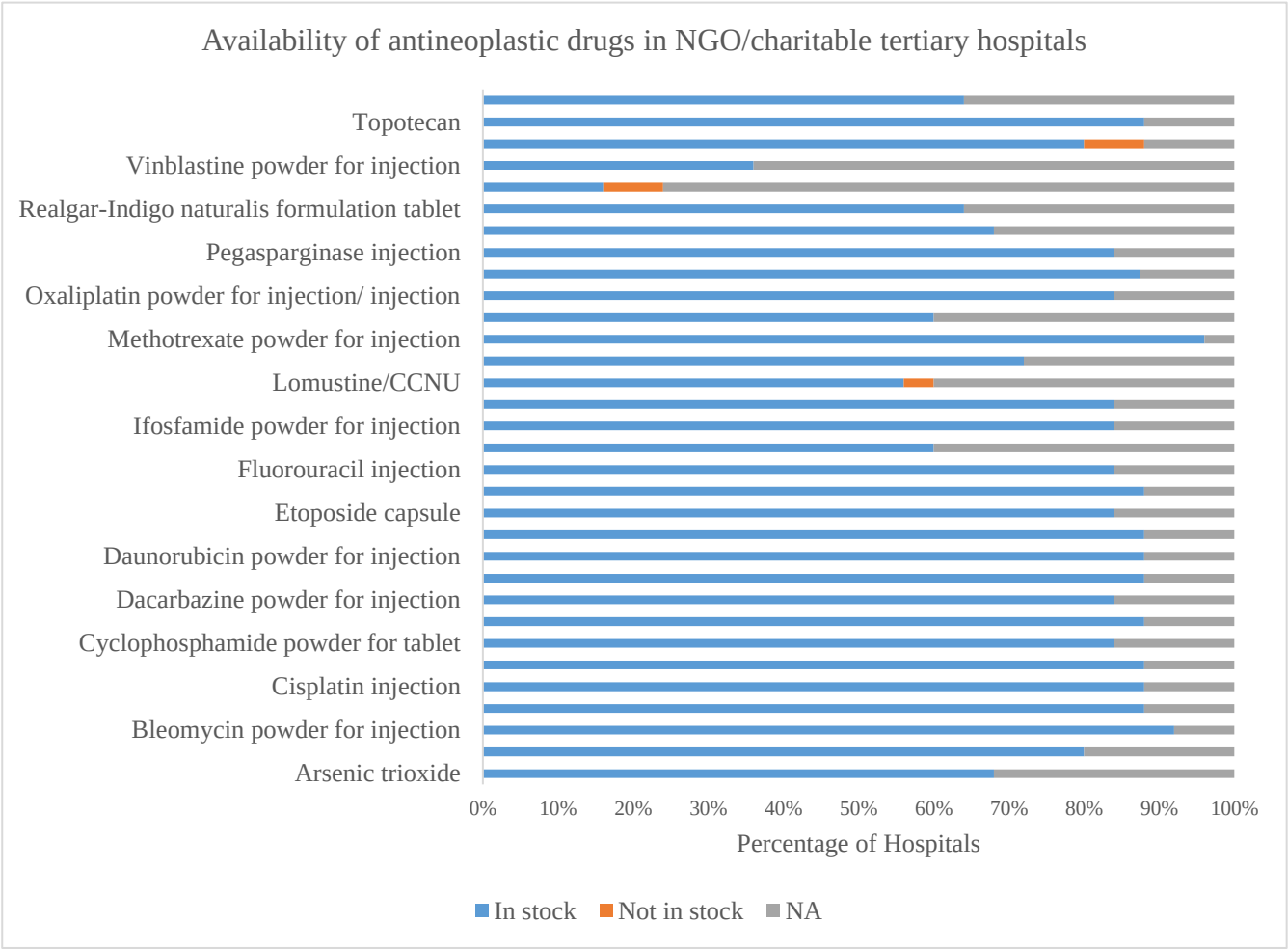

Fig. 64

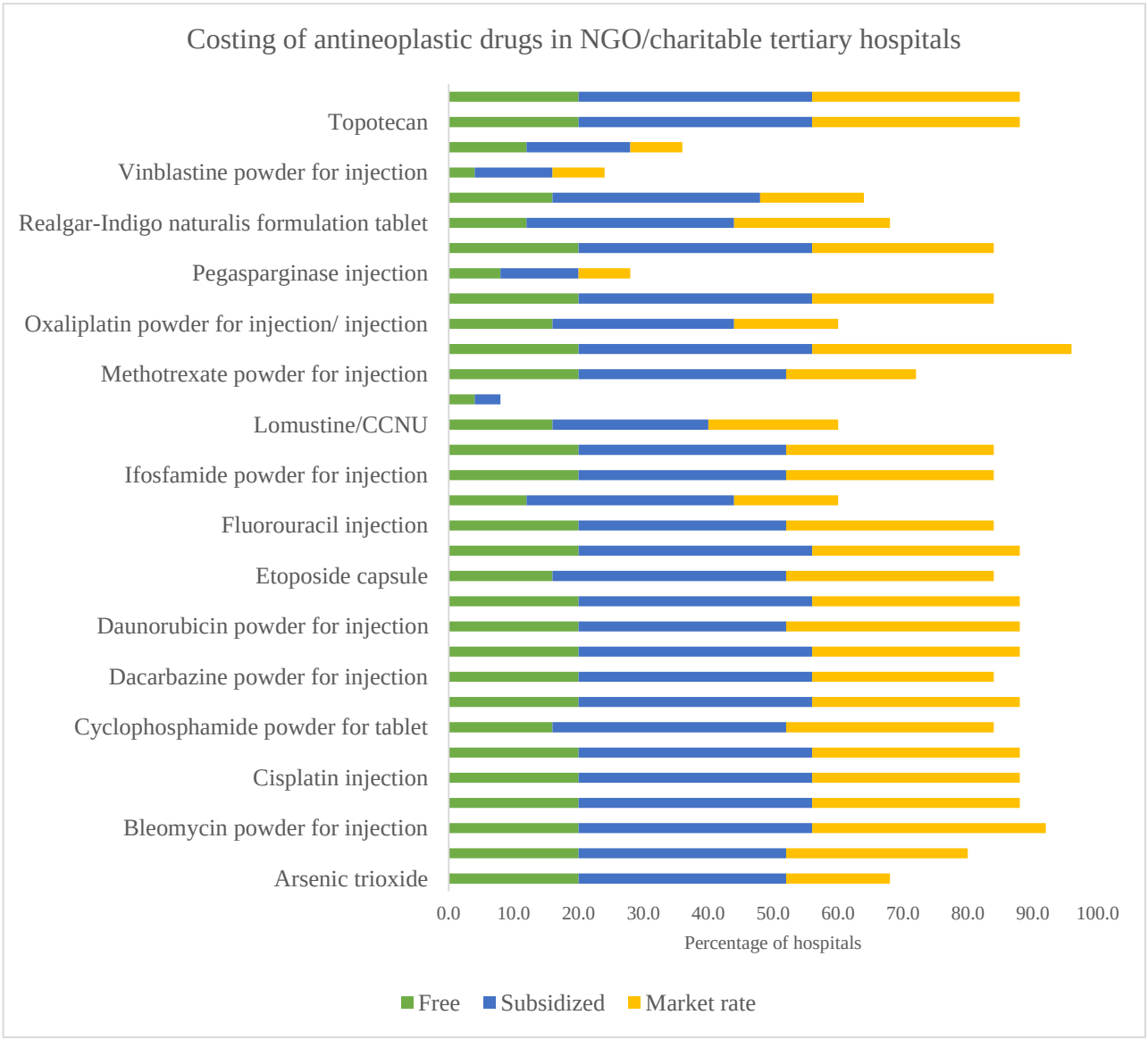
Costing of antineoplastic drugs in NGO/charitable tertiary hospitals
Topotecan
Vinblastine powder for injection
Realgar-Indigo naturalis formulation tablet
Pegasparginase injection
Oxaliplatin powder for injection/ injection
Methotrexate powder for injection
Lomustine/CCNU
Ifosfamide powder for injection
Fluorouracil injection
Etoposide capsule
Daunorubicin powder for injection
Dacarbazine powder for injection
Cyclophosphamide powder for tablet
Cisplatin injection
Bleomycin powder for injection
Arsenic trioxide
0.0
10.0
20.0
30.0
40.0
50.0
60.0
70.0
80.0
90.0
100.0
Percentage of hospitals
Free
Subsidized
Market rate

Fig. 65

17. Reasons for treatment denial and treatment abandonment

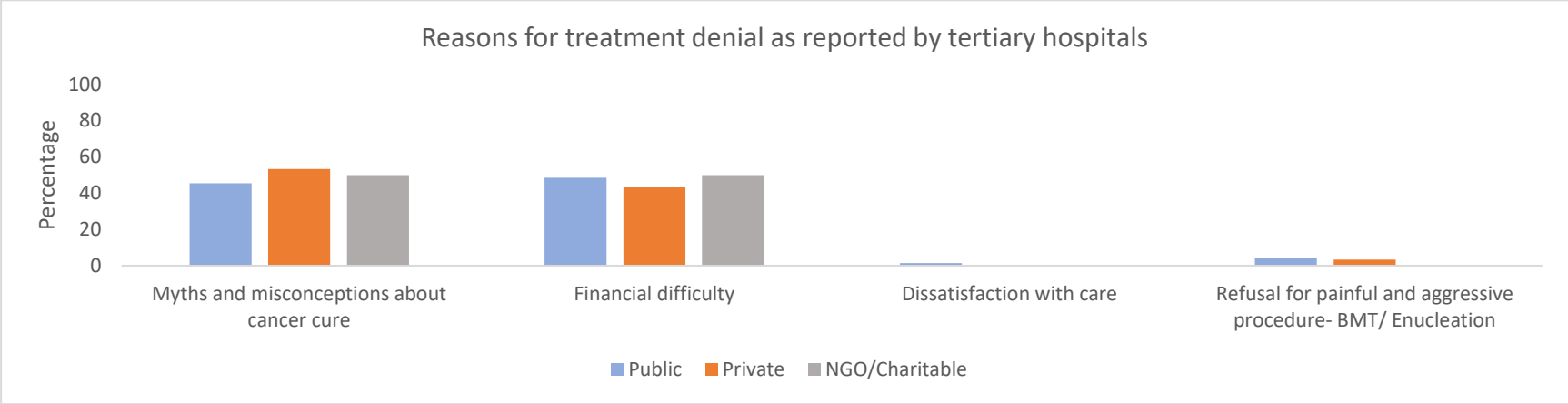

Fig. 66

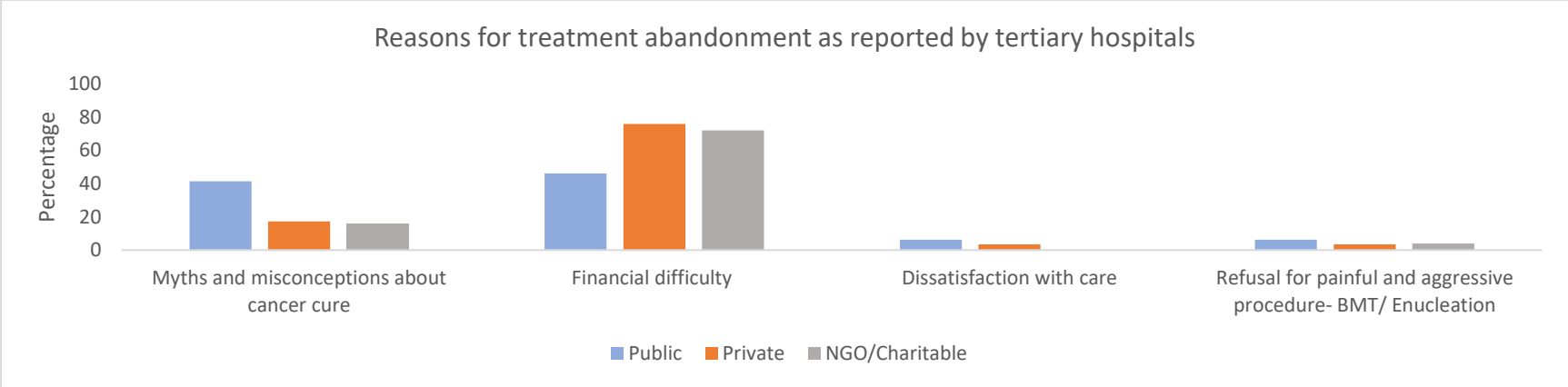

Fig. 67

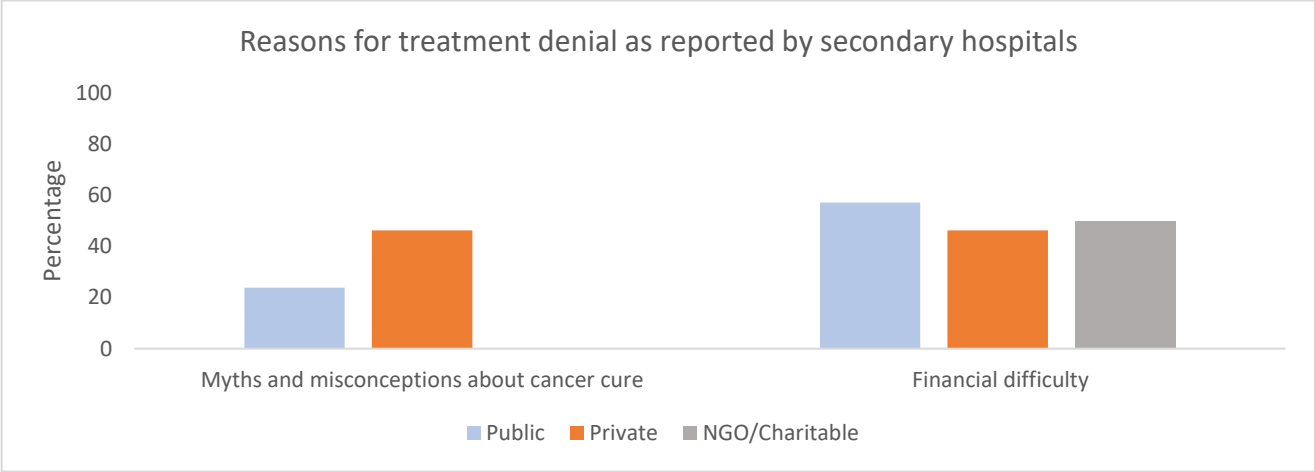
Reasons for treatment denial as reported by secondary hospitals
100
80
60
40
20
0
Percentage
Myths and misconceptions about cancer cure
Financial difficulty
Public
Private
NGO/Charitable

Fig. 68

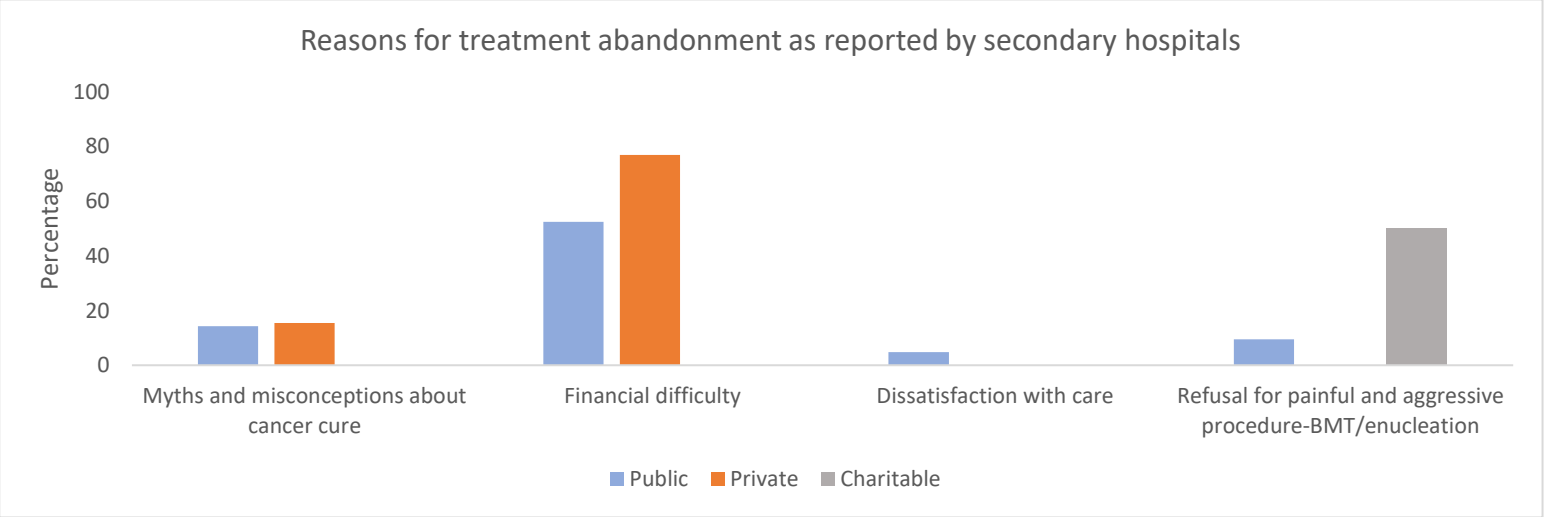
Reasons for treatment abandonment as reported by secondary hospitals
100
80
60
40
20
0
Percentage
Myths and misconceptions about cancer cure
Financial difficulty
Dissatisfaction with care
Refusal for painful and aggressive procedure-BMT/enucleation
Public
Private
Charitable

Fig. 69

Table 24: Delivery of childhood cancer care services at tertiary hospitals impacted by COVID pandemic

S. No.	Delivery of childhood cancer care services	Public (n = 77)		Private (n = 35)		NGO/ charitable (n = 25)	
		n	%	n	%	n	%
Impact of COVID 19 pandemic on the delivery of childhood cancer care services at the hospital		**44**	**57.1**	**18**	**51.4**	**13**	**52.0**
1.	Complete closure of paediatric cancer care services	3	6.8	0	0	1	7.6
2.	Ceased evaluating new cases of suspected cancers	14	31.8	3	16.6	3	23.0
3.	Decrease in new paediatric cancer diagnoses	31	70.4	11	61.1	10	76.9
4.	Increase in treatment abandonment	32	72.7	9	50.0	9	69.2
5.	Reduced surgical care	20	45.4	8	44.4	4	30.7
6.	Modifications in chemotherapy regimens	25	56.8	8	44.4	9	69.2
7.	Interruptions in radiotherapy	21	47.7	9	50.0	5	38.4
8.	Unavailability of chemotherapy agents	17	38.6	6	33.3	3	23.0
9.	Shortage of blood products	21	47.7	9	50.0	9	69.2
10.	Telemedicine use	21	47.7	4	22.2	6	46.1

Annexure 7 - Snapshot of database

State wise Data Status

Sl No.	State / U.T	Tertiary			Secondary			State Nodal Officer			NGOs		
		Total	Partial	Completed	Total	Partial	Completed	Total	Partial	Completed	Total	Partial	Completed
1	Andhra Pradesh	5	0	5	5	0	5	0	0	0	0	0	0
2	Arunachal Pradesh	1	0	1	2	0	2	1	0	1	0	0	0
3	Assam	4	0	4	4	0	4	1	0	0	0	0	0
4	Bihar	5	0	3	1	0	1	0	0	0	0	0	0
5	Chandigarh	2	0	2	1	0	1	1	0	0	0	0	0
6	Chhattisgarh	5	0	5	1	0	1	1	0	1	0	0	0
7	Gujarat	3	0	3	2	0	2	1	0	1	0	0	0
8	Haryana	9	0	9	1	0	1	0	0	0	0	0	0
9	Himachal Pradesh	0	0	0	0	0	0	0	0	0	0	0	0
10	Jammu and Kashmir	4	0	4	2	0	2	1	0	1	0	0	0
11	Jharkhand	3	0	3	2	0	2	1	0	1	0	0	0
12	Karnataka	6	0	5	8	0	6	1	0	0	1	0	1
13	Kerala	11	0	10	5	0	5	1	0	1	1	0	1
14	Madhya Pradesh	5	0	5	5	0	5	1	0	0	0	0	0
15	Maharashtra	11	0	11	1	0	1	1	0	1	6	0	2
16	Manipur	4	0	4	1	0	1	1	0	0	0	0	0
17	Meghalaya	1	0	1	5	0	5	0	0	0	0	0	0
18	Mizoram	5	0	5	4	0	4	0	0	0	0	0	0
19	Nagaland	3	0	3	4	0	3	1	0	1	0	0	0
20	New Delhi	8	0	8	7	0	7	1	0	0	3	0	3
21	Odisha	3	0	3	2	0	2	1	0	1	1	0	1
22	Puducherry	3	0	3	0	0	0	1	0	1	0	0	0
23	Punjab	6	0	6	7	0	7	1	0	1	0	0	0
24	Rajasthan	5	0	5	4	0	1	1	0	0	0	0	0
25	Sikkim	2	0	2	1	0	1	1	0	1	0	0	0
26	Tamil Nadu	4	1	3	2	0	1	1	1	0	0	0	0
27	Telangana	5	0	5	5	0	5	1	0	1	0	0	0
28	Tripura	5	0	5	5	0	5	2	0	1	0	0	0
29	Uttar Pradesh	6	0	6	4	0	4	1	0	1	0	0	0
30	Uttarakhand	4	0	4	5	0	5	1	0	0	0	0	0
31	West Bengal	5	0	1	5	0	3	1	0	1	1	0	1
	Total	143	1	134	101	0	92	26	1	16	13	0	9

Annexure 8- Statistical terms

1. Mean, or Average – Sum of all the observations (X_1, X_2, X_3 X_4, X_5, ……. X_N) divided by the total number of observations (N)

2. Proportion or percentage – Percentage is a ratio or proportion multiplied by 100 and is a relative value expressed per hundred.

3. The weighted sum was used to calculate availability by therapeutic category as was used in another study
   The percentage availability of drugs in a therapeutic family is calculated using the following formula

$$\sum \frac{n_i * 100}{M * N}$$

where

- n_i is the number of drugs within a particular category available at a hospital
- N is the total number of drugs in a particular category as mentioned in the survey form
- M is the total number of hospitals being surveyed

References

Arora B, Banavali SD. Pediatric oncology in India: Past, present and future. Indian J Med Paediatr Oncol. 2009 Oct;30(4):121-3.

Arora B, Kanwar V. Childhood cancers in India: burden, barriers, and breakthroughs. Indian J Cancer. 2009 Oct-Dec;46(4):257-9

Arora RS, Eden TO, Kapoor G. Epidemiology of childhood cancer in India. Indian J Cancer. 2009 Oct-Dec;46(4):264-73. doi: 10.4103/0019-509X.55546.

Arora, R. S., & Bakhshi, S. (2016). Indian Pediatric Oncology Group (InPOG) – Collaborative research in India comes of age. PHOJ Pediatric Hematology Oncology Journal, 1(1), 13–17.

Bhopal SS, Mann KD, Pearce MS. Registration of cancer in girls remains lower than expected in countries with low/middle incomes and low female education rates. Br J Cancer. 2012 Jun 26;107(1):183-8.

Brownson RC, Fielding JE, Green LW. Building capacity for evidence-based public health: reconciling the pulls of practice and the push of research. Annual review of public health. 2018 Apr 1;39:27.

Ganguly S, Kinsey S, Bakhshi S. Childhood cancer in India. Cancer Epidemiol. 2021 Apr;71(Pt B):101679. doi: 10.1016/j.canep.2020.101679. Epub 2020 Feb 6. PMID: 32033883.

ICMR-NCDIR. Clinicopathological Profile of Cancers in India: A Report of the Hospital Based Cancer Registries, 2021.

Maiti R, Bhatia V, Padhy BM, Hota D. Essential Medicines: An Indian Perspective. Indian J Community Med. 2015 Oct-Dec;40(4):223-32

Manikandan S, Gitanjali B. National list of essential medicines of India: the way forward. J Postgrad Med. 2012 Jan-Mar;58(1):68-72.

Medical Facility Registration. Available from: https://vmc.gov.in/vmcdocs/OMRF/3.%20Definitions.pdf

Mehta PS, Wiernikowski JT, Petrilli JA, Barr RD; Working Group on Essential Medicines of the Pediatric Oncology in Developing Countries committee of SIOP. Essential medicines for pediatric oncology in developing countries. Pediatr Blood Cancer. 2013 May;60(5):889-91

National Cancer Institute. Chemotherapy. Available from: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/chemotherapy

National cancer Institute. Medical oncologist. Available from: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/chemotherapy

National Health mission. Nutrition Rehabilitation Centre. Available from: https://nhm.assam.gov.in/frontimpotentdata/nutrition-rehabilitation-centre-nrc

National List of Essential Medicines.2015Available : https://www.nhp.gov.in/NHPfiles/NLEM%2C%202015.pdf

Ngaihte P, Zomawia E, Kaushik I. Cancer in the NorthEast India: Where we are and what needs to be done? Indian J Public Health. 2019 Jul-Sep;63(3):251-253. doi: 10.4103/ijph.IJPH_323_18.

NHP. Glossary. Available from: https://www.nhp.gov.in/glossary_mtl

Pan American Health Organization. Early Diagnosis of Childhood Cancer. Washington, DC: PAHO, 2014.

Report of National Cancer Registry Programme (ICMR-NCDIR), Bengaluru, India 2020 https://www.ncdirindia.org/All_Reports/Report_2020/default.aspx

Shanta V. First Pediatric Oncology Unit in India at the Cancer Institute (WIA), Chennai. Indian J Med Paediatr Oncol. 2010 Jul;31(3):101-2.

Specchia, M.L., Frisicale, E.M., Carini, E. et al. The impact of tumor board on cancer care: evidence from an umbrella review. BMC Health Serv Res 20, 73 (2020). https://doi.org/10.1186/s12913-020-4930-3

Steliarova-Foucher E, Colombet M, Ries LAG, Moreno F, Dolya A, Bray F, Hesseling P, Shin HY, Stiller CA; IICC-3 contributors. International incidence of childhood cancer, 2001-10: a population-based registry study. Lancet Oncol. 2017 Jun;18(6):719-731.

WHO list of priority medical devices for cancer management. World Health Organization, 2017.

World Health Organization Health Systems Strengthening Glossary. Available from: https://cdn.who.int/media/docs/default-source/documents/health-systems-strengthening-glossary.pdf?sfvrsn=b871d95f_4

World Health Organization. Child health and development, Information, education and communication. Available from: http://www.emro.who.int/child-health/community-information/information/All-Pages.html

World Health Organization. Drug and Therapeutics Committee Training Course—Participants' Guide. Available from: https://www.who.int/medicines/technical_briefing/tbs/10-PG_Standard-Treatment-Guidelines_final-08.pdf

World Health Organization. Palliative care. Available from: https://www.who.int/news_room/fact-sheets/detail/palliative-care

World Health Organization. Regional guidelines for continuing medical education (CME. WHO Regional Office for South-East Asia; 2010.

World Health Organization. Service Availability and Readiness Assessment (SARA)An annual monitoring system for service Delivery-Reference Manual, 2015.https://usermanual.wiki/Document/SARAReferenceManual.138510287/view

World Health Organization. Telemedicine- opportunities and developments in member states. Available from: https://www.who.int/goe/publications/goe_telemedicine_2010.pdf

World Health Organization. WHO model list of essential medicines for children. Geneva: World Health Organization, 2021.Available from: https://apps.who.int/iris/bitstream/handle/10665/345533/WHO-MHP-HPS-EML-2021.02-eng.pdf

Yadav H, Shah D, Sayed S, Horton S, Schroeder LF. Availability of essential diagnostics in ten low-income and middle-income countries: results from national health facility surveys. Lancet Glob Health. 2021 Oct 5:S2214-109X(21)00442-3

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