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Health Systems for Rehabilitation – Critical Appraisal of the National Programme for Stroke in India.

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ABSTRACT

The organized provision of health services in India has been envisioned since 1946 by the recommendations from the Bhore committee. However, the policy and program strategies for the provision of good quality health care still lack effectiveness. Access to rehabilitation services for persons with disabilities continues to be a significant public health problem in India. This review intended to identify the barriers to integration and implementation of rehabilitation services within the national program for stroke in India. The methods involved the critical review and appraisal of the last five years of the published common review mission reports which report the performance of the entire health system and national program of the country. All relevant policy and program documents related to the national program for the prevention and control of cancer, diabetes, cardiovascular diseases, and stroke, were also reviewed. The World Health Organization, Rehabilitation 2030 recommendations were also cross-compared to summarize the findings from the critical review. The results revealed that rehabilitation was neglected within the conceptualization and implementation of the NPCDCS program. Let alone for the Stroke program, there was not any evidence-based description of the concept of disability management and rehabilitation within the NPCDCS program. The health system in its current form appears to be a non-inclusive system for disability-inclusive development. The priority is mainstreaming disability within the agenda for the health of the nation. If disability could be mainstreamed within the health agenda of India and in LMICs, universal health coverage and disability-inclusive development can certainly, be achieved.

KEYWORDS- Health Policy; Health Systems; Rehabilitation; Disability; Inclusive Development; Policy Analysis.

INTRODUCTION

Health Systems in India:

India is a federal union with 28 states and eight union territories.[1] Health is a state subject in India where the state government takes up the responsibilities to provide good quality health care and public good to the people in each state.[2] Organized provision health services in India have been envisioned since 1946 by the recommendations from the Bhore committee.[3]

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However, the policy and program strategies for the provision of good quality health care still lack effectiveness.[4] This had in fact led to the emergence of private health care systems in India which is currently being utilized by a significant proportion of the country's citizens, especially those living in urban areas.[4-5] India has a health care system where the public and private sectors work simultaneously and sometimes in partnership to meet the health needs of the population.[6] The private health system is primarily located in urban areas and provides secondary and tertiary healthcare services.[6] The government health system is three-tiered covering primary, secondary, and tertiary level care and health services for the entire state supported by the national ministry of health and family welfare (MoHFW) (Figure -1).[2,7] This system has improved significantly in the past two decades in terms of its approach to meet the increasing health needs of people in the country.[8] Given the epidemiological transition in the second-most populous country in the world, there have been several strategic re-organization of the health system with new national programs for non-communicable diseases, mental health, elderly care, as well as health insurance policies converged under the new National Health Mission (NHM).[2, 7-8]

However, the tertiary prevention aspects such as disability and rehabilitation have been neglected and are hardly visible in any of this strategic reorganization.[9-11] Access to rehabilitation services for persons with disabilities is an important public health problem in India.[7, 12] Comprehensive rehabilitation services are available only in tertiary care hospitals situated in urban areas and they are predominantly run by physicians and physiotherapists.[12 -16] Disability and rehabilitation are viewed only from a charity model especially by the government systems through the ministry of social justice and empowerment and it is restricted to the provision of monthly pension and livelihood opportunities.[12-16] The health system in its current form appears to be a non-inclusive system for disability-inclusive development.

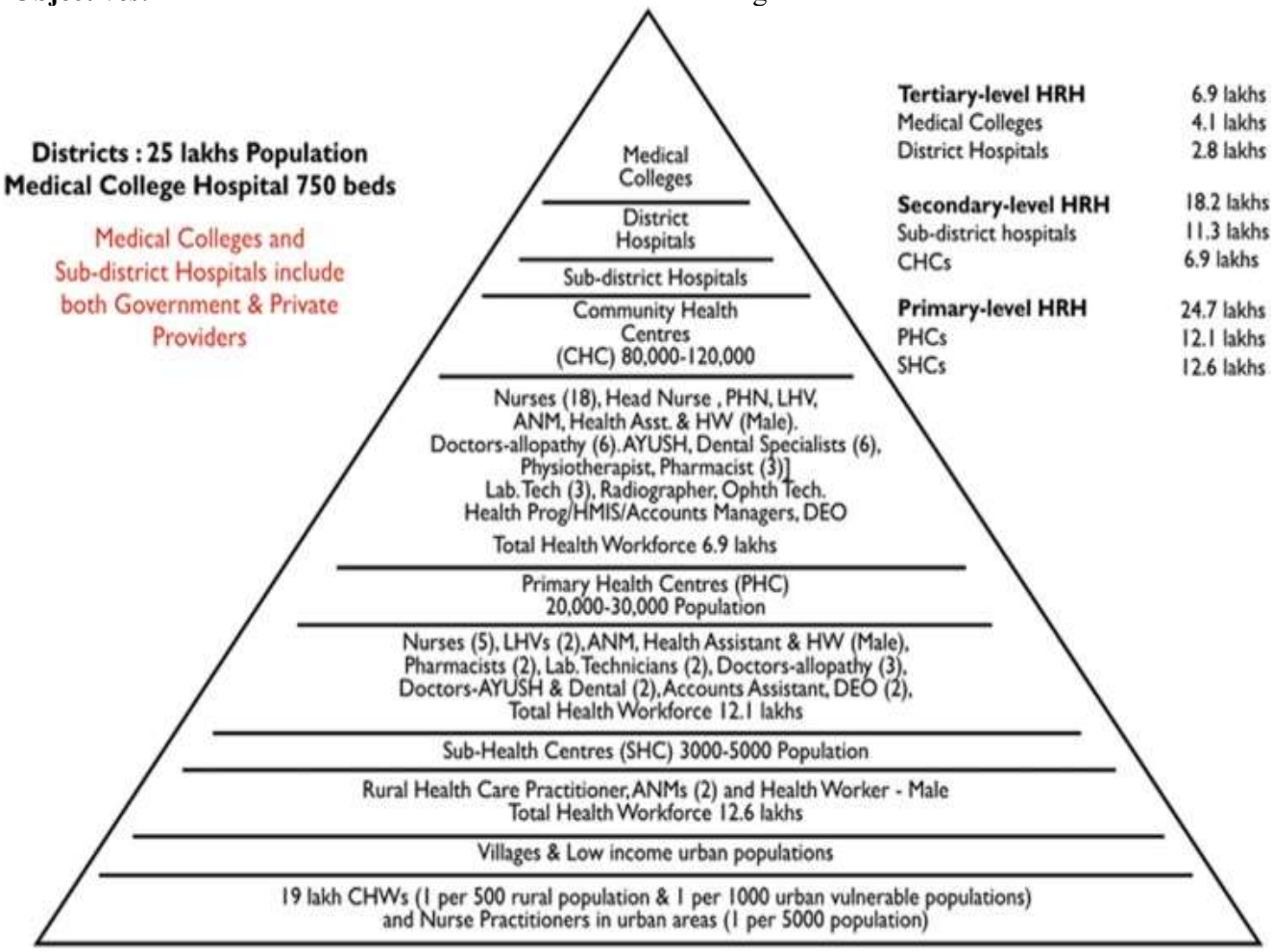
National Program for Stroke in India:

The National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) is the only program that was designed to cover Stroke or cerebrovascular disease initiatives in the country.[17] The NPCDCS was launched in 2006 and was piloted in 2008 in selected states and then rolled out to all states a decade ago. The objective of this program was to prevent and control non-communicable diseases (NCDs) including stroke through the establishment of NCD clinics at the community level and opportunistic screening for NCDs at the primary health centers (PHCs) and Sub-health centers (SHCs) in the villages. Screening, capacity building, community awareness, treatment, and management of complications were the core program activities within the government health facilities and NCD clinics in the community.[17] However, there is very little understanding and effort on the impact of these activities on the stroke survivors experiencing disabilities and the consequences leading to their poor quality of life. Although more than a decade and a half since its inception, the NPCDCS program has still not been effective enough to reduce the growing burden of stroke and stroke-related disabilities in India.[18-20] Recent evidence on the magnitude of stroke in India very clearly highlights the unchanging and rather increasing incidence and prevalence of stroke.[21] This implies the importance of identifying the barriers to effective implementation of the NPCDCS program and developing scalable solutions to address the disability burden imposed by stroke and other NCDs in India.

Common Review Mission:

The Common Review Mission (CRM) is an extensive national monitoring exercise of the national health mission. This initiative has been in place since 2007.[22-23] The primary objective of the CRM is to enhance the focus of the NHM on a fully functional health system at all levels in the country. The CRM reviews all the national health programs, policies, and strategies of the NHM from the perspectives of the community to ensure people with health needs can access good quality service, free of cost in any place within the country.[22-23] The CRM reviews have been even more rigorous since within the expanded service delivery package of the health systems.[22] Having been scaled up in all 2018 particularly because, most of the national programs have been operationally strengthened

Figure-1: Health systems in India[2]



the states since 2015, the NPCDCS program has been reviewed majorly as a part of the CRM. Hence this review includes all the program evaluation reports of the NPCDCS program within the CRM reports from 2015 to 2019 until the last review mission, published by the MoHFW.

Objectives:

- To review the barriers to integration and implementation of rehabilitation services within the national program for stroke in India.

METHODOLOGY

The methods involved the critical review and appraisal of the last five years of published CRM Reports and all relevant and published policy as well as program documents related to NPCDCS from MoHFW. CRM Reports from 2015 – 2019 were reviewed to understand the barriers to integration and implementation of the disability and rehabilitation aspects of the stroke program within the NPCDCS evaluation summaries in the reports.[24-28] Some of the findings from the evaluation reports are presented as it is in boxes for the purpose of description. The World Health Organization (WHO) Rehabilitation 2030 action plans were also cross-compared to summarize the findings from the critical review.[29]

Health System Barriers for Rehabilitation within the NPCDCS Program:

The review of the programs and policy documents related to the NCDs and NPCDCS was useful to identify the Barriers to integration and implementation of rehabilitation within the national program for stroke in India. The Details are provided below.

Non-Inclusive development of the NPCDCS Program: The review identified that the NPCDCS

program development was non-systematic and non-inclusive in its approach. Rehabilitation was neglected within the conceptualization of the NPCDCS program.[24-28] Let alone for the Stroke program, there was not any evidence-based description of the concept of disability management and rehabilitation within the NPCDCS program covering all NCDs.[17-19]

between 2012 – 2017.[31] This is excluding the cost it might incur for managing disability and rehabilitation of those experiencing disabilities due to NCDs and especially after a stroke which results in various neurological disabilities.

Table:1 Comparison of the review findings with the WHO Rehabilitation in Health systems recommendations

Rehabilitation 2030 Recommendations	Strength	Quality of Evidence	NPCDCS Stroke Program
Rehabilitation services should be integrated into health systems	Conditional	Very Low	Not Integrated
Rehabilitation services should be integrated into and between primary, secondary, and tertiary levels of health systems	Strong	Very Low	Physiotherapy services integrated with Tertiary level
Financial resources should be allocated to rehabilitation services to implement and sustain the recommendations on service delivery	Strong	Very Low	Not Allocated
Where health insurance exists or is to become available, it should cover rehabilitation services	Conditional	Very Low	No insurance Cover for rehabilitation
Both community and hospital rehabilitation services should be available	Strong	Moderate	Available only in tertiary hospitals. CBR-Non-existent
A multi-disciplinary rehabilitation workforce should be available	Strong	High	Rehabilitation is restricted to physiotherapy services
Hospitals should include specialized rehabilitation units for inpatients with complex needs	Strong	Very High	Not present

"In no state was there an understanding that public health facilities at primary health care level offered services, be it screening, examination or treatment, with the result that those who sought care at public health facilities tended to access CHC or DH incurring higher cost, and the possibility of poor treatment adherence and lack of follow up, resulting in fragmentation of care" **CRM 2018**

A review of the operational guidelines of NPCDCS clearly indicated that the program was developed primarily for addressing the cancer burden in the country.[30] **Incorporation of stroke and other NCDs appears to be deliberate and for reducing managerial and administrative bottlenecks**.[30]

The program was piloted in 100 districts in 21 states between the period of 2010-2012 in India. Bottlenecks were identified and the program was re-strategized as well as scaled up to the entire country.[17-19] A total amount of INR 80960 million was allocated for implementing these strategies

A new guideline exclusively for stroke had been published under the NPCDCS program in 2019.[32] There were about 12 pages within the document on rehabilitation, describing the role of physiotherapists and envisioning recruitment of one physiotherapist at the tertiary level in the districts to meet the growing need for stroke rehabilitation.[32] Overall, it is evident that none of those who are involved in the rehabilitation of persons with disabilities were included in conceptualizing the national program. Although the 2019 document exclusive for stroke starts with an inclusive statement on the need for multi-disciplinary rehabilitation, conceptualization strategies and operational plans exclude the entire system for disability and rehabilitation required to implement this program effectively. A cross-comparison of the recommendations from the WHO rehabilitation 2030 against the existing situation of the NPCDCS program is provided in Table – 1.

Lack of health systems for rehabilitation:

> "Lack of follow up mechanisms for positively diagnosed case is a critical challenge, and in absence of records for identified cases it is difficult for service providers to follow up for treatment compliance". **CRM 2019**

A review of the CRM reports in the past five years reveals that even the existing strategies lack the system that is required for the rehabilitation of persons with disabilities following a stroke.

Human resources:

> "Human Resource shortages in NCD cells at district and state levels service delivery at the secondary level of health care facilities constrain continuum of care". **CRM 2019**

The first and foremost issue reported in the CRM evaluation was the lack of human resources for the entire program.[24-28] Even in the 2019 guidelines for stroke, opportunistic screening and case detection outside the hospital setting and, in the communities, especially at the primary level care (PHCs and SHCs) were envisioned only through Accredited Social Health Activists (ASHAs) and Anganwadi Workers (AWWs).[32] Although AWWs and ASHAs play a crucial role in primary care, they are non-qualified, non-permanent government healthcare workers, already implementing close to 20 national programs apart from the NPCDCS.[2] Even specific training related to disability management and rehabilitation for those involved in NPCDCS was not reported in any of the CRM evaluations.[24-28] The NHM is reforming the PHCs into Health and Wellness Centres (HWCs) to accommodate the management of NCDs and there isn't any dedicated, qualified rehabilitation workforce such as physiotherapists, occupational therapists, rehabilitation nurses, clinical psychologists, speech-language pathologists, orthotist in these HWCs.

> "It is not surprising that in all states, Out of Pocket Expenditures for those with hypertension and diabetes was largely on medicines, transport with multiple visits to the health care facility". **CRM 2018**

Health Management Information Systems (HMIS):

Enumeration of those detected with high risk for NCDs including stroke was not able to be followed up in the absence of health records.[24-28] Although a surveillance system is envisioned for the entire NPCDCS program, there are issues reported in relation to the absence of health records to enable service providers to follow up and ensure compliance. Organized HMIS systems and effective follow-up mechanisms have been in place within the national programs for HIV/AIDS and Tuberculosis in NHM previously.[24-28] However, it's surprising to see such systems either integrated or newly established for NPCDCS within the NHM to date. Without the HMIS for identifying individuals who need rehabilitation, it is impossible to ensure a continuum of care to those who need it most and reduce the disability burden in India.

Health Financing:

There was an absence of any funding allocation or expenditure for rehabilitation-related activities in the INR 85000 million rupees allotted between 2012-2017 for the NPCDCS program.[31] This needs to be critically looked at because there is a lack of insurance coverage for stroke rehabilitation especially outside the institutional settings such as tertiary care hospitals even within the Ayushman Bharat program as well as from the private sector.[24-28] Each year, 55 million people in India become poorer in order to pay healthcare costs, and 38 million falls below the poverty line due to spending on medications alone.[33] The situation is very similar for those individuals diagnosed with stroke or other NCDs. The prescription for medicines to these group individuals was only dispensed for a week to 10 days maximum at the public facilities at all levels in India. The affected individuals are expected to travel to these health facilities once in 10 days and request for a repeat prescription or wait in the long queue for a significant amount of time to get this medicine free of cost. If not, these diagnosed individuals generally get the medicines from the nearest private pharmacy paying for them.[24-28] This implies a significant Out Pocket Expenditure (OOPE) or opportunity cost on the affected individuals to get their medicines to protect themselves from the risk

of a stroke or NCDs and manage the complications of it.

Equipment and Supplies: Given the issues related to medicine, it must be assumed that the equipment

> "Continuum of care is essential for Non-Communicable Diseases' management and control; however, referral and follow up mechanisms were weak across the states. None of the states reported back referral of identified NCD patients undergoing treatment at higher health care facilities". **CRM 2019**

and supplies related to disability and rehabilitation, such as orthotics, wheelchairs, assistive devices, supports, and splints remain unavailable in the government health supplies.[27-28] These rehabilitation supplies and equipment might be unavailable at the pharmacies of MoHFW. They might be expensive even if available and non-specific to the needs of the affected individual in private pharmacies and suppliers. There are not any stroke-specific provisions to receive prescriptions for devices like a wheelchair, shoulder sling, ankle-foot orthoses specific to the needs of the stroke survivors even in the scheme for assistance to disabled persons for purchase of aids and appliances (ADIP) by the ministry of social justice and empowerment.[34]

Service Delivery:

There are three ways in which services for the stroke component of the NPCDCS program were delivered. First is at the tertiary hospitals where individuals experiencing a stroke get admitted and treated for a stroke.[24-28] In these facilities, stroke survivors might be able to receive physiotherapy services for 3-5 days within their acute care stay. Rehabilitation services are restricted primarily to physiotherapy for these 3-5 days during the acute care in these facilities. There are very few multi-disciplinary stroke rehabilitation institutions with free in-patient facilities in the entire country. Secondly, the individuals at risk of a stroke can be screened routinely at the NCD clinic and could avail prescription for their medicines at NCD clinics.[24-28] There is a plan since 2019 to integrate complementary medicine such as Ayurveda, Yoga, Unani, Siddha, and Homeopathy (AYUSH) systems of Indian medicine and have these doctors at NCD clinics.[24-28] This is expected to dilute the existing evidence for rehabilitation services as well as compensate for all other required human resources. Lastly, individuals can be screened in the community by ASHAs and AWWs. However, in the absence of any basic rehabilitation service provision facilities within the health or social care

> "In Bihar, the NPCDS programme was reported to be non-functional, including the availability of equipment and drugs for hypertension and diabetes". **CRM 2016**

sector at the villages and blocks, follow-up, compliance, and continuum of care can only be dreamt.

Health Policies for rehabilitation:

None of the CRM reports, policy, and program documents reviewed, reported on policies for disability and rehabilitation for persons with disabilities in general, let alone for people affected by stroke or NCDs.[24-28] This implies that the evidence of the absence of any policy for rehabilitation in India is the reason for the absence of any evidence related to the presence of systems for disability management and rehabilitation in the country. It is evident that the NPCDCS as well as the other national program planners, implementers, and policymakers are well-aware of the lack of a health system for rehabilitation and hence the operational framework or the strategy document lacks any information about disability and rehabilitation.

The way forward - Mainstreaming rehabilitation within the agenda for Health

Comparing the recommendations from WHO on rehabilitation in health systems with the findings from this review unveil what's essential and what must be prioritized by the national health system stewards in India and in similar countries. The priority is mainstreaming disability within the agenda for the health of the nation. The MoHFW must take up the responsibility for the rehabilitation and integrate rehabilitation within its health system. Currently, the integration is limited to tertiary hospitals without the conceptualization of disability as recommended by the International Classification of Functioning from a bio-psycho-

social perspective.[31] Although the medical model for rehabilitation is just emerging in the urban areas of the country. Disability even from a medical model does not imply impairments alone and physiotherapists, ASHAs, AWWs cannot be considered as a comprehensive multi-disciplinary rehabilitation team for reducing the burden of disability in any country. This conceptualization can enable disability-inclusive integration right from the HWCs in the grass root. There is a high level of evidence for multi-disciplinary rehabilitation, especially in tertiary care facilities for people with complex health and rehabilitation needs such as stroke survivors.[32] Sufficient allocation of funding for rehabilitation with adequate supplies and mechanisms to reduce OOPE like the insurance for rehabilitation of NCDs such as stroke must be prioritized. In the absence of a system for rehabilitation, inclusive development can only be dreamt. Perhaps this is an important reason why stroke is still the leading cause of disability in the past four decades in India. If disability could be mainstreamed within the health agenda of India, universal health coverage and disability-inclusive development can certainly be achieved.

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