Webinar Report

Release of the Report – Home Healthcare: Emerging Phenomenon in India

15 March 2023

Presentation of the Study findings

The demand for home healthcare services has grown significantly in recent years due to the rising elderly population, and epidemiological and sociocultural changes taking place in the country. It further rose during the COVID-19 pandemic. However, there are concerns regarding the availability, quality and cost of home healthcare services, safety of the providers, grievance redressal mechanisms, and regulation of the sector.

Considering the dearth of information, Health Systems Transformation Platform (HSTP) conducted a study titled, '**Home Healthcare: Emerging Phenomenon in India**', co-authored by Ms. Pallavi Gupta and Dr. Sonali Randhawa. The study draws attention to the home healthcare landscape in the country with the objective to understand how home healthcare is organised and delivered, with respect to the services, providers and users, and the interaction between them.

A webinar was organised on 15 March 2023 to release the report of the study, share its key findings, and initiate a discussion on the opportunities and challenges facing home healthcare in India, and steps to address the concerns related to it. The recording of the webinar is available here.

About 90 researchers, practitioners, academicians, government representatives, civil society members, journalists and students attended the webinar. Mr. Rajeev Sadanandan (CEO, HSTP) welcomed all the participants and spoke about the emergence of home healthcare in India, its potential role in addressing the needs of the transitioning Indian society, and the reason why HSTP decided to work on it. He stated that the home healthcare market was bound to have diverse characteristics, which the current study emphasises, as it has grown arbitrarily without any planning. Dr. Sonali Randhawa (Research Associate, Health Systems Governance, HSTP) shared the background, objectives and methodology of the study. Ms. Pallavi Gupta (Specialist, Health Systems Governance, HSTP) presented the study findings, an overview of – services, users, providers, and organisations engaged in the sector and how such services are delivered in India.

The presentation was followed by a discussion with the participants.

- Dr. Ajay Mahal (Professor, University of Melbourne, Australia) suggested the need for quantitative data to assess the need for home healthcare. Others also advocated that there is a need to quantify the home healthcare sector, including the number of home healthcare centres/organisations, the size and scope of private home healthcare organisations, etc.
- Prof. Rama Baru (Professor, Jawaharlal Nehru University, India) suggested that the diversity and typology of home healthcare be captured based on the findings of the study.
- Concerns regarding biomedical waste management in home healthcare were brought up by Dr. Shyamala Mani (Public Health Foundation of India and Centre for Chronic Disease Control). Since the study highlights the type of services and common procedures performed at home, it was mentioned that it may be possible to enlist the type of biomedical waste commonly generated in home healthcare.

- Some other questions raised by the participants were related to the role of the state and central clinical establishments regulations, certification of home healthcare companies, the amount of time spent by family members caring for patients at home, studies on the impact of paying for home healthcare on household financial well-being, among others.

This was followed by a panel discussion.

Panel Discussion

The panellists were Dr. Gowri Nambiar Sengupta (Deputy Director General - Public Health, Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India), Ms. Kavita Narayan (Technical Advisor, Human Resources for Health/Health Systems for Public Health, Ministry of Health and Family Welfare, Government of India), Dr. P K Jameela (Member, Kerala State Planning Board, Government of Kerala) and Ms. Anupama Datta (Head, Policy Research and Advocacy, HelpAge India). They shared their perspectives on home healthcare in India and provided insights on the aspects that going forward need attention.

Opening the panel discussion, Ms. Kavita Narayan, congratulated the team for conducting the study considering the size of the home healthcare market, which is worth USD 340 billion worldwide. She observed that there is an increasing need for home healthcare services and providers not just in India but across the world, which is both an opportunity as well as the reason to address the associated challenges. She shared that the Ministry of Health and Family Welfare (MoHFW) is the nodal agency to standardise the skill curricula related to healthcare. In the last four to five years, MoHFW has reviewed about 107 curricula, including those for home health aides, geriatric care aides, biomedical waste technicians, etc., that are offered by the Healthcare Sector Skill Council (HSSC), National Skill Development Corporation under the Ministry of Skill Development and Entrepreneurship. She highlighted some of the issues – lack of avenues to connect trained providers with the home healthcare organisations and users, both the providers and users being unaware of the standards to be followed in delivering home healthcare, and the high cost of hiring home health aides given that the majority of services are provided by the private sector. Another gap is the absence of a digital database of professionals who have completed skill-training courses. There is, therefore a need to create a digital platform where both the provider and the user may be connected, which was also pointed out by Dr. Dinesh Baswal (Lead MNCH, PATH) during the discussion.

The next speaker on the panel was Ms. Anupama Datta who mentioned that home healthcare in India largely operates in an unorganised manner. Since it has always been the family's responsibility to care for patients at home, the practice of hiring paid providers for home caregiving services is new and evolving. Secondly, home healthcare is dominated by the private sector, which is unorganised and unregulated, leading to a high cost of services. Home healthcare organisations are opposed to the idea of the sector becoming organised as they would then have to ensure that trained providers deliver services at home, labour laws are met along with other regulatory requirements. The Ministry of Social Justice and Empowerment introduced the

Maintenance and Welfare of Parents and Senior Citizens (Amendment) Bill, 2019, in an effort to regulate the organisations that provide care for the elderly, including old age homes, home healthcare organisations, etc. However, the amendment is still pending and no regulatory body is in place to govern home healthcare.

Dr. Gowri Nambiar Sengupta, who oversees national programmes for the elderly, palliative care, and mental health, provided insights about government strategies related to home healthcare. Under the National Programme for Health Care of the Elderly, components of home-based care are integrated into the Ayushman Bharat – Health and Wellness Centres with defined roles for healthcare workers. These workers are provided training, as well as regular monitoring, assessment, and line listing of those who require home-based care. There is also a concept of peer support groups. For example, in Tamil Nadu, there are peer groups of elderly women who take care of bed-bound patients and in Jharkhand, there are *Sahiyas and Sahiya sathis*, local government functionaries who manage the information of people in need of home-based care in the community. Similarly, state governments have also developed their own models of providing palliative care, for example, Tamil Nadu has palliative care units manned by physiotherapists and staff nurses; in Kerala, departments of social welfare, health and local self-government collectively deliver palliative care at home. She reiterated the fact that there are no regulations in home healthcare and emphasised the need for a common definition of the term, given the diversity that exists. She further added the Central Government faces challenges regarding developing the quality of care standards, in accordance with state requirements; users do not demand quality services or trained providers, even in the private sector; users prioritise elder and palliative care only when it interferes with their daily activities. Dr. Sengupta also urged the participants to consider the physical and emotional dependencies that patients develop on the providers and the lack of assessment of assistive aides and technologies that people are often compelled to use at home.

Dr. PK Jameela shared the Government of Kerala's strategy to deal with the changing demographics and the role of home healthcare in it. She mentioned that the state has a well-functioning palliative care programme, however, elder care did not receive as much attention from the government until recently. She further added that domestic care and home healthcare services are mixed up in Kerala. The high demand for such services is fulfilled mostly by untrained people and private organisations have adopted several non-standardised curricula for training. The registration process followed by the organisations is not uniform across the state – home healthcare organisations are not covered under the Kerala Clinical Establishment (Registration and Regulation) Act 2018, but some companies have registered with the labour department and the panchayat. Therefore, there is a need to develop a regulatory mechanism for the registration of organisations, standard operating procedures to deliver care, standard training curricula, ensure care quality, and deliver care to people who cannot afford these services. Panchayats are required to assume responsibility moving ahead, and decentralisation may be an approach to delivering home healthcare services. The Kerala State Planning Board is planning to conduct a preliminary survey to learn about the state's current situation in home healthcare, Dr. Jameela added.

The key issues that emerged during the discussion were as follows:

1. Cost of care and affordability is a major issue in home healthcare. The organisations have limited incentive to hire trained providers as it increases the cost of services which not many people can afford.

Dr. Gowri N. Sengupta, expressed her concerns about the elderly using insurance, particularly private insurance and stressed on the role of government insurance to be explored further. In her opinion, under the Maintenance and Welfare of Parents and Older Citizens Act of 2007, families are required to pay for elder care, or it has to be self-financed; those who are unable to pay may receive assistance from the state government.

Dr. Ajay Mahal argued that relying solely on family assistance could not be a long-term solution because of declining fertility rates, smaller family sizes, and households with fewer young adults to take care of the elderly. In addition to family support, peer-based or community-based support may be taken into consideration as is done in Malaysia. Long-term universal health coverage in Germany is another strategy, however, he also cautioned that long-term insurance should not be viewed differently given the current issues with India's healthcare system. With the changing demographics, there is a need to bring in additional resources and pool people from the informal sector to make home healthcare affordable.

Dr. Arin Dutta (Senior Health Specialist, Asian Development Bank) commented that community-based models are currently being studied in Asia in response to the lack of financing for long-term/home geriatric care, yet, it is unclear how it will support nursing services or medicalised needs at home. Ms. Rathi Balachandran (Assistant Director General (Nursing), MoHFW, Govt. of India) added that contributory health insurance could be another approach. It was concluded, that there is a need to consider a multipronged financing approach that targets people with non-communicable diseases, persons with disabilities, and the elderly, with particular attention paid to women, people residing in rural areas and those who may not be able to pay themselves.

2. Lack of policy environment regarding the registration and operations of home healthcare organisations.

Mr. Tom George (CEO, Guardian Angel Homecare, Kochi, Kerala) addressed the issue of registration of home healthcare companies. He emphasised that it is not necessary to register with the health department and that, like any other business in Kerala, his company first registered with the labour commission office, the municipal corporation's health department, and other relevant local departments. He has obtained professional indemnity and fidelity insurance licences, modelling his company after the home healthcare of the United States of America; and his company has received accreditation certification from the Quality and Accreditation Institute. He voiced concerns about the standard of training that government institutions provide to general duty assistants (GDAs) and that the government's focus is usually on quantity (increasing the number of providers) rather than quality.

3. It is important to define the ecosystem of home healthcare, otherwise it is difficult to draw the line between healthcare and domestic care.

Prof. Rama Baru stressed on the importance of defining the ecosystem of home healthcare and its boundaries, using an interdisciplinary approach. She mentioned that since the market is only meeting the needs of the middle and upper middle classes, it is important to study the class dimension to understand the fragmentation of demand and supply of healthcare services at home. She also raised the aspect of feminisation of domestic work because there is a gendered aspect to caring and it has always been the duty of the women of the house. She suggested looking into China's public insurance scheme, as it covers home-based care for the elderly population.

4. Dr. Gowri Sengupta brought up the dichotomy between the Ministry of Health and Family Welfare and the Ministry of Social Justice and Empowerment with regard to who will regulate what. Going forward, there is a need to define what is needed to be provided, to whom and for how long, and where and how would the regulation be.

5. The discussion brought up several issues related to trained caregivers, such as the quality of training, varied nomenclature, low demand for skill courses related to home healthcare, the attrition rate of providers, supervision at home and employment and career progression opportunities. Hence, it was felt that the current approach that focuses only on training individuals without offering adequate support to continue in the role is unlikely to succeed.

Concluding the session, Mr. Sunil Nandraj (Advisor, HSTP) raised certain issues for further consideration, such as the role of the state, whether it is a provider, financier, or regulator; the use of regulations given the state's capacity to implement them; the need to decide who and what should be regulated and where to draw the line; issues related to urban and rural population; and other forms of provision of services, for example, online aggregators; grievance redressal mechanism for both users and providers in home healthcare.

Mr. Sadanandan summarised the discussion and underlined the need for collaboration to address the various concerns in home healthcare. He observed that the study by HSTP is a first step and calls for more work to understand it comprehensively before providing policy interventions. He expressed his gratitude to all those present for their active participation and for advancing the conversation on home healthcare.

Way Forward

The webinar highlighted various issues that challenge the provision of healthcare services at home in India. Mentioned below are some such issues for further deliberation and action:

- Assess the need for home healthcare in states.
- Develop a common understanding of what home healthcare encompasses and standardise its typology.
- Develop standard operating protocols by condition/user category/service.

- Need to explore mechanisms to make home healthcare services accessible and affordable to people according to their requirements.
- Create awareness among the users about what to expect in home healthcare and how to access the services as well as among the providers about their role, rights and responsibilities while delivering the services.
- Review the quality of training and skill set of the people who undergo skill-training courses.
- Connect the trained providers, home healthcare organisations and users digitally through an online database of trained providers.
- Need to establish grievance redressal mechanisms for both users and providers in home healthcare.
- Integrate other mechanisms to deliver healthcare services at home, for example, using telemedicine through Health and Wellness Centres, and the role of community/peer support groups in home healthcare.
- Advocate changing the common perception of caregiving in home healthcare as being a "dirty job" by promoting it as a respectable and dignified employment opportunity to encourage the trained providers to take up these roles.

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The webinar report 'Home Healthcare: Emerging Phenomenon in India' is developed by Health Systems Transformation Platform (HSTP) to share the summary of proceedings of the discussion.

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