Home Healthcare Emerging Phenomenon in India

Pallavi Gupta Sonali Randhawa

Health Systems Transformation Platform New Delhi, India



HOME HEALTHCARE EMERGING PHENOMENON IN INDIA

Pallavi Gupta Sonali Randhawa

February 2023

Health Systems Transformation Platform (HSTP)

C1 Block, ISID, 4, Institutional Area, Phase II, Vasant Kunj New Delhi – 110070, India



Disclaimer

Health Systems Transformation Platform (HSTP) is a not-for-profit organization registered under the name of Forum for Health Systems Design and Transformation; a company licensed under section 8 of the Indian Companies Act 2013. Our mission is to enable the Indian health system to respond to people's needs. We do this in collaboration with Indian & Global expertise through research for health systems design, enhancing stakeholders' capabilities and fostering policy dialogue.

We also strive to enable Indian researchers and policymakers to conduct research and translate evidence for achieving Universal Health Coverage. We collaborate with Indian & Global expertise by strengthening stakeholder capabilities for health systems redesign, validating interventions, and fostering policy dialogue.

HSTP activities are financially supported by Sir Ratan Tata Trusts. HSTP is committed to the highest standards of ethics and professional integrity in all its endeavours and declares no conflict of interest on account of its funding arrangements. The contents of this report should not be attributed to, and do not represent the views of the funders. HSTP and its partners have taken all reasonable precautions to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for interpreting and using the material lies with the reader. In no event shall HSTP and its partners be liable for damages arising from its use.

In case of any queries or suggestions contact, Pallavi Gupta, at pgupta@hstp.org.in | For more details visit https://www.hstp.org.in/

Suggested Citation: Gupta P., & Randhawa S. (2023). Home Healthcare: Emerging phenomenon in India. Health Systems Transformation Platform, New Delhi

ISBN: 978-81-949194-1-4

CONTENTS

Foreword	i
Acknowledgements	ii
Abbreviations	iii
Executive Summary	iv
Introduction and Background	1
Methodology	6
Home Healthcare Services	13
Home Healthcare Users	16
Home Healthcare Providers	19
Organisations Engaged in Home Healthcare	24
Financing and Regulation of Home Healthcare	31
Challenges and Opportunities in Home Healthcare	36
Conclusion	42
References	44
Annexures	49
Annexure I: Characteristics of Respondents	49
Annexure II: Interview Guides	52
Annexure III: Government Recognised Home Healthcare related Vocatio	nal Courses59
Annexure IV: Curriculum of Vocational training courses	62

Foreword

Home healthcare is gaining popularity in India on account of the increasing elderly population, the growing prevalence of chronic illnesses, the changing family structure and advances in healthcare technology. The COVID-19 pandemic drew further attention to the expanding size and scope of home healthcare in the country.

The experience gleaned from other countries indicates that home healthcare has acquired diverse meanings and purposes according to context. Several media articles and market analysis reports have been highlighting the growing need for home healthcare in India. However, there is a dearth of literature on what constitutes home healthcare, and how it is organised and delivered in the country. In 2021, Health Systems Transformation Platform (HSTP) released a report, 'Regulation of Health Care Delivery in India – A Landscape Study', in which we reviewed the central laws that regulate healthcare delivery. Our review showed that one of the areas where the regulatory structure lacks clarity is home healthcare. Considering the role that home healthcare can potentially play in addressing the needs of the transitioning Indian society, it becomes important to ascertain how the sector is structured at present. Such information would contribute to informed planning, delivery and access to healthcare services at home while taking advantage of the country's social capital and demographic dividend.

With this in mind, HSTP conducted an exploratory study to understand how home healthcare is organised and delivered, with respect to the services, providers and users, and the interaction between them. The study gives an overview of financing, government policies and regulations in home healthcare, and vocational training programmes for caregivers.

I thankfully acknowledge the support and cooperation of all the study respondents who took out time to offer their insights and experiences in home healthcare.

We hope that the study will stir a discussion on this topic, which has not garnered much policy and programme attention thus far and contribute to the planning and standardisation of home healthcare services.

Rajeev Sadanandan

Chief Executive Officer, Health Systems Transformation Platform (HSTP)

Acknowledgements

This study would not have been possible without the support and contribution of several people who we would like to acknowledge.

We are grateful to all the respondents – the patients, their families, healthcare providers, managers, heads of organisations and subject matter experts, who agreed to take part in the study and shared their knowledge, experience and concerns related to home healthcare.

We are thankful to the members of the HSTP Institutional Ethics Committee who reviewed the study proposal and offered recommendations that helped in improving it.

We would like to thank our colleagues at HSTP, Dr Kumaravel Ilangovan, Dr Pratheeba John and Mr Sanjeev Kumar for their assistance during data collection. Furthermore, we would like to acknowledge with much appreciation the support provided by the HSTP team.

Dr Mithun Som and Dr Geeta Narayan reviewed the draft report. Their insightful comments helped in bringing clarity to the report and in identifying areas for further research.

Mr Sunil Nandraj, Advisor, HSTP, guided us throughout the study, helped in the conceptualisation and development of the study design, and reviewed multiple drafts of the report.

Mr Rajeev Sadanandan, CEO, HSTP, has always encouraged us to pursue new areas of work. He motivated us to explore the issue of home healthcare and shared his valuable inputs.

Finally, we would like to thank Sir Ratan Tata Trusts for their continued support and financial assistance to undertake this study.

Abbreviations

ADL: Activities of Daily Living

ANM: Auxiliary Nurse and Midwife

ASHA: Accredited Social Health Activist

COVID-19: Coronavirus Disease 2019

BMW: Biomedical Waste

CRDs: Chronic Respiratory Diseases

CVDs: Cardiovascular Diseases

DALYs: Disability-Adjusted Life Years

EDQ: Exploratory Descriptive Qualitative

GDA: General Duty Assistant

GNM: General Nursing and Midwife

GoI: Government of India **HHA**: Home Health Aide

HIV/AIDS: Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

IADL: Instrumental Activities of Daily Living

ICU: Intensive Care Unit

LASI: Longitudinal Ageing Study in India

MoHFW: Ministry of Health and Family Welfare

MSDE: Ministry of Skill Development and Entrepreneurship

MSJE: Ministry of Social Justice and Empowerment

NCDs: Non-Communicable Diseases

NGO: Non-Government Organisation

NHM: National Health Mission

NITI Aayog: National Institution for Transforming India Aayog

NSDC: National Skill Development Corporation

NSS: National Sample Survey

OECD: Organisation for Economic Cooperation and Development

QAI: Quality and Accreditation Institute

SOP: Standard Operating Procedures

TFR: Total Fertility Rate

WHO: World Health Organization

EXECUTIVE SUMMARY

The care provided to ill or infirm people in their homes is referred to as home healthcare, also known as home-based care or home care. It encompasses preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care. The overall goal of home healthcare is to provide care to people so that they can maintain their quality of life and independence at home.

In India, the rising elderly population, and epidemiological and sociocultural changes are driving the demand for home healthcare, similar to the experience of European and other Asian countries. India is expected to add another 311 million people to its current population of 1.21 billion by 2036. States like Kerala, Tamil Nadu, and Himachal Pradesh are predicted to have a higher elderly population than youth. Approximately 62 percent of disabled people in India require a caregiver, and nearly one-fifth of all disabled people are elderly. In 2016, the proportion of deaths caused by non-communicable diseases (NCDs) increased to 61.8 percent, and nearly 65 percent of NCD deaths occur before the age of 70 years. At the same time, the cancer burden is increasing in the country and nearly six million people are estimated to need palliative care annually.

There is a dearth of information about the services, providers and organisations that offer home healthcare in India, notably the private, for-profit, home healthcare companies. Considering the rising need and the growth that this sector is experiencing, Health Systems Transformation Platform (HSTP) reviewed the home healthcare landscape in the country. An exploratory descriptive qualitative (EDQ) study was undertaken to: (i) understand what comprises home healthcare, with regard to the services, users, providers and different types of organisations engaged in home healthcare, and (ii) explore the interaction between the users, providers and organisations engaged in home healthcare. A total of 24 in-depth interviews and one expert consultation were conducted between February and May 2022, to complement the information gathered from the literature review. The data was analysed using thematic analysis. The scope of the report is restricted to services and providers of the western system of medicine.

Services: From being confined to assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL) until about a decade ago, services at home now include medical care. The routine nursing care services at home comprise monitoring of vitals, dressing of wounds and bedsores, intravenous or intramuscular injections, etc. There is a growing provision of post-hospitalisation intensive care, monitoring and stabilisation services through a hospital-like environment at home, palliative care, and physiotherapy services at home. Better paying capacity among a section of the population and availability of clinical care at home due to technological advancements have contributed to the expansion of the basket of services.

Users: Healthcare services at home are in high demand for the elderly population who mostly require ADL and IADL assistance along with routine nursing care. Patients who

need follow-up care after being discharged from the hospital, people with physical, mental, or intellectual disabilities, and those with musculoskeletal conditions are among the other significant users. During the pandemic, people with COVID-19 were the key users of home healthcare services.

Providers: The providers of home healthcare in India can be divided into five categories – family members, community-based outreach workers, untrained aides, trained caregivers who undergo vocational training and professionally qualified healthcare workers. Family members, usually women, are often the primary carers for sick or incapacitated persons at home. Community-based outreach workers deliver services at home as part of government and non-government programmes for specific groups such as pregnant women, newborns, geriatric populations, cancer patients, etc.

Most common providers of at-home services are the untrained aides and trained caregivers who undergo vocational training. Untrained aides/attendants/ayahs primarily help with ADL and IADL, lack formal training in assisted living and learn with experience. Trained caregivers, commonly referred to as home health aides/geriatric care aides/general duty assistants, are skilled to deliver patient care and assistance with daily living activities. Professionally qualified healthcare workers such as doctors, nurses, physiotherapists, counsellors, etc. also provide home healthcare services. The untrained aides, trained caregivers and professionally qualified healthcare workers offer services independently when hired directly by users, or through home healthcare organisations.

Organisations engaged in home healthcare: Hospitals, home healthcare companies, non-profit organisations, and nursing bureaus are examples of organisations that offer home healthcare. These organisations offer services ranging from routine to specialised nursing care, intensive care, geriatric care, assistance with activities of daily living, etc. Private, for-profit, home healthcare companies are relatively new but fast expanding. Private hospitals have started their own home healthcare departments that tend to patients discharged from their hospital. Some non-profit organisations focus on palliative care, geriatric care and bedridden/dependent patients.

The organisations deliver services at home through temporary providers and on-roll staff, though they are inclined towards engaging the former on a need basis to minimise their liability. Some home healthcare organisations have developed internal processes such as performing the patient's medical assessment and home assessment before initiating a service; conducting periodic training of providers; and supervising the providers deployed at patients' homes. While some organisations draw a written contract with the families, others usually function on verbal understanding. In case of an emergency, it is the family's responsibility to take the patient to the hospital.

Financing and regulation of home healthcare: Though the demand for home healthcare services has grown significantly in the recent years, there are concerns related to their cost, availability of providers and their safety, and the regulation of services. In the present scenario, only a small section of the population can afford healthcare services

at home as they are mainly provided by the private, for-profit sector. While specialised services such as intensive care may be cheaper at home than in hospital, the cost of hiring a provider at home is high. For instance, hiring a nurse for a month, for a 24-hour service can cost up to INR 1,00,000, and a trained caregiver can cost up to INR 40,000. Coverage of home healthcare services under medical insurance is limited to certain post hospitalisation conditions based on the doctor's prescription. The long duty hours within the confines of the patient's home make a provider's job strenuous. Instances of verbal and sexual misconduct by the patients and their families also add to the providers' reluctance to work in the home environment. The healthcare services at home are not governed by any regulations leading to arbitrariness in the sector. The amendment proposed through the Maintenance and Welfare of Parents and Senior Citizens (Amendment) Bill 2019, could be the first step towards regulating home healthcare, even if applicable only to elderly care.

The report draws attention to an essential and expanding but under-researched aspect of the healthcare system in India. The home healthcare sector largely operates informally with little quality control and no grievance redressal mechanism for the users or the providers. Future studies may explore in greater detail the user and provider perspective, as well as the accreditation and quality aspects. The healthcare system in the country ought to be prepared to meet the needs of the elderly population and offer long-term care to people with disabilities and chronic conditions. For this, further discussions are required to develop a comprehensive understanding of home healthcare in India and establish standardised processes.

INTRODUCTION AND BACKGROUND

Home healthcare is an emerging phenomenon in India. The two main reasons for this are demographic and epidemiological shifts taking place in the country.

Already the second largest population in the world (1.21 billion, Census 2011), India is estimated to add another 311 million people by the year 2036 (National Commission on *Population, 2020*). The population share of youth is expected to decline during this period from 27.2 percent in 2021 to 22.7 percent (Ministry of Statistics and Programme Implementation, 2022); while states such as Kerala, Tamil Nadu and Himachal Pradesh are projected to see a higher elderly population than youth (Magazine, 2022). The age structure of the nation is changing because of the continuing fertility reduction and longer life span. The total fertility rate (TFR) in India has decreased to 2.0, below the replacement level of 2.1, and is estimated to be 1.6 in urban areas and 2.1 in rural areas (International Institute for Population Sciences, 2020). Thus, while on one hand, there are fewer births, on the other, India's elderly population has been steadily growing because of improved life expectancy. Nearly 104 million people, or 8.6 percent of the total population, were over the age of 60 years in 2011, and that number is expected to rise to 10 percent by 2020 and nearly 15 percent by 2036 (National Commission on Population, 2020). At the same time, opening up of the economy at the turn of the 21st century and growing employment opportunities in cities have contributed to greater urbanisation (Agarwal, 2020). These changes have altered the family structure and lifestyle significantly, with traditional familial support on the decline and smaller and nuclear families becoming the norm.

Non-communicable diseases (NCDs) are more prevalent than communicable diseases in India. The proportion of deaths from non-communicable diseases rose from 37.9 percent in 1990 to 61.8 percent in 2016, according to the study 'India: Health of the Nation's States. The India State-Level Disease Burden Initiative' (Indian Council of Medical Research et al., 2017). India had 4.7 million deaths in 2017 due to NCDs, with the primary causes being cardiovascular diseases (CVDs, 23 percent), chronic respiratory diseases (CRDs, 9 percent), cancer (6 percent), and diabetes (2.4 percent). Additionally, 226.8 million disability-adjusted life years (DALYs)—or 47 percent of all DALYs in India—are attributable to NCDs (Menon et al., 2022). The onset of NCDs is happening as early as age 45 years. According to estimates, about 65 percent of NCD deaths occur before the age of 70, especially among Indians between the ages of 30 and 70 (Arokiasamy, 2018; Menon et al., 2022). The estimated cancer burden in India in 2021 was 26.7 million DALYs (Kulothungan et al., 2022). Nearly six million people are estimated to need palliative care

in the country annually (Khosla et al., 2012). Home-based palliative care has shown to be a successful model for providing care to people with diseases like cancer (Yeager et al., 2016). There are 26.8 million differently abled persons in India comprising 2.21 percent of the country's population (Census of India, 2011). Of these, about 20 percent have disability in movement, 19 percent have visual disability, 19 percent have hearing disability and 8 percent have multiple disabilities. The elderly disabled constitute almost one-fifth of the total disabled at the all-India level. According to the Survey of Persons with Disabilities in India conducted during the National Sample Survey (NSS) 76th round (July-December 2018), nearly 62 percent of the persons with disabilities require a caregiver (Ministry of Statistics and Programme Implementation, 2021). Additionally, since 1990, the proportion of mental health conditions in India's total burden of diseases has nearly doubled (Sagar et al., 2020). It may be possible to better manage people with mental health conditions such as dementia and support their caregivers through homebased care (Dias et al., 2008). The healthcare system needs to be prepared to meet the requirements of the growing elderly population and long-term care in case of people with chronic conditions. Timely diagnosis and appropriate management can help in increasing longevity and improving the quality of life (Malik et al., 2021).

The relevance of home healthcare is rising in India because of the sociocultural, epidemiological, and demographic transition, much like the global experience seen in several Organisation for Economic Cooperation and Development (OECD) countries and Asian countries like Thailand and Indonesia (Welch et al., 1996; Genet et al., 2012; Pacific Bridge Medical, 2014; Kiersey & Coleman, 2017).

Home healthcare

The care provided to ill or infirm people in their homes is referred to as home healthcare, also known as home-based care or home care. The overall goal of home healthcare is to provide people with care so that they can maintain their quality of life and independence at home. It comprises preventive, promotive, therapeutic, rehabilitative, long-term maintenance, and palliative care. It may be provided by formal and/or informal caregivers and may include both clinical and non-clinical services (Western Cape Government, 2013; WHO Initiative on Home-Based Long-Term Care, 2002). In addition to doctors and nurses, an interdisciplinary team of professionals comprising social workers, rehabilitation therapists, dieticians, pharmacists, psychologists, etc., may provide home healthcare (Landers et al., 2016).

People who may require home healthcare are those with chronic illnesses or conditions like hypertension, diabetes, HIV/AIDS, mental illness, renal conditions, cancer, agerelated conditions, etc. People who require extended care but not necessarily hospital care, such as those who are recovering from illnesses or surgeries, people with disabilities and the elderly who require care for age-related health concerns, including assistance with daily living activities, can also benefit from home healthcare.

Global context

The global experience shows that the demand for home healthcare increases with changing demographics, disease profile of the population and sociocultural transition. Rise in the population of the elderly, increase in chronic diseases and a shift toward smaller families drives the demand for home healthcare upward. This has been observed in practically all the countries that have witnessed such changes, such as the United States of America; European nations like Germany, the Netherlands and Scotland; as well as Asian nations like South Korea, Japan, Thailand and Indonesia (Welch et al., 1996; Genet et al., 2012; Pacific Bridge Medical, 2014; Kiersey & Coleman, 2017). In the USA, home healthcare was originally meant to reduce hospital stay and facilitate early discharge. As a result, it could only be used for post-hospitalisation care under the government insurance programme. However, after realising that home health services were frequently used for long-term care of persons with chronic diseases, this condition was eliminated in 1980 (Welch et al., 1996). According to estimates, the percentage of people 65 years and above in European nations will rise from nearly 18 percent in 2005 to 30 percent in 2050 (Tarricone, R. et al., 2008). Additionally, by 2050, there will likely be only two people in the working age group for every person over 65 years (Genet et al., 2012). Such demographic change has influenced the provision of home care services in several European countries. For instance, countries such as Germany and the Netherlands have an insurance-based system that covers home nursing and social care services. There are also voluntary, charitable, and for-profit providers of home care services. Since 1992, municipalities in Denmark have offered home care (Tarricone, R. et al., 2008). In countries such as Scotland and Sweden too, policy and legislation are directed toward caring for elderly citizens in the home rather than in institutions (Genet et al., 2012; Kiersey & Coleman, 2017).

Japan is one of the most rapidly ageing countries, with the number of people 65 years and older steadily rising from 7.1 percent in 1970 to 16.2 percent by 1998 and 26.9 percent by 2020. Nurses began home visits in the late 1970s to address the healthcare needs of the elderly. The Government of Japan introduced a long-term care insurance programme in 2000. The insurance system covers home care services such as home help, visiting nurse service, respite care, rehabilitation, medical check, healthcare equipment and devices, and housing reorganisation, among others (Murashima et al., 2002; Pacific Bridge Medical, 2014). In South Korea, under the Elderly Welfare Act of the Government of South Korea, home care services have been made available since 2008 to those 65 years or older, younger people with disabilities or chronic illnesses, or people with difficulties in daily living activities, for at least six months. (Won, 2013; Ga H, 2020). Thailand is also witnessing an increase in the number of people who need home healthcare services. It is anticipated that by 2040, 32.0 percent of the population will be 60 years of age or older up from 16.7 percent in 2017 (Pimdee & Nualnetr, 2017). After trying out various models of home and community-based care, the Thai government adopted a policy in 2016 to provide long-term care services to the elderly in their homes. Medical services, including preventive services, physiotherapy, rehabilitative and assistive devices, are available through the programme and covered under the universal health package (*Pagaiya et al., 2021*). It is evident that several countries have or are in the process of developing their own model of home healthcare, adapted to their local context and resources (*Genet et al., 2012*).

Rationale and need for the study

The importance of home healthcare was established during the COVID-19 pandemic in India. Remote monitoring as well as home visits by doctors, nurses and trained volunteers, coupled with the use of equipment such as pulse oximeters, thermometers, oxygen concentrators, oxygen cylinders, essential drugs etc., at home came to the rescue of many. While private hospitals offered home care packages at pre-defined costs, state governments also offered similar services, sometimes in collaboration with home healthcare companies (Nandi, 2020). For instance, state governments in Delhi and Karnataka partnered with home healthcare companies for home-based management of patients suffering from COVID-19 (NITI Aayog, 2021a), though there were concerns about costs charged to both the state governments and individual patients (Porecha, 2020). Thus, though home healthcare as a commercial form of service in India is relatively new, its role proved significant during the COVID-19 pandemic. This was particularly so in the months of April and May 2021, when the country reported record cases of 3,00,000 to 4,00,000 per day, and beds in hospitals were unavailable (Pandey, 2021).

The Indian home healthcare market, valued at approximately USD 6.2 billion in 2020 is expected to grow four times to USD 21.3 billion by 2027. As per estimates, home healthcare has the potential to replace up to 65 percent of unnecessary hospital visits in India and reduce hospital costs by 20 percent (NITI Aayog, 2021b). Though the need for home healthcare and its role in the health sector in India is increasing, there is sparse documentation about how services are organised and delivered at home. Hence, this study was conducted with the following objectives.

Objectives

The overall objective of the study was to explore how healthcare services are provided to people in their homes.

The specific objectives of the study were to:

- 1. Understand what comprises home healthcare.
- 2. Explore the interaction between patients, providers and organisations engaged in home healthcare.

The research questions were:

- 1. Which healthcare services are provided at home?
- 2. Who uses healthcare services at home?

- 3. Who provides healthcare services at home?
- 4. Which organisations deliver healthcare services at home and how?5. What are the barriers and opportunities in delivering healthcare services at home?

METHODOLOGY

The study was designed as an Exploratory Descriptive Qualitative (EDQ) study to gain familiarity with the spectrum of home healthcare services, the providers, users and the arrangement between different stakeholders while delivering healthcare services at home. The EDQ approach, based on the work of Stebbins (2001) and Sandelowski (2000, 2010), is recommended to explore aspects of healthcare practice that have previously received "little or no attention" (Hunter et al., 2018). Hence it is suitable for the underresearched phenomenon of home healthcare. Stebbins suggests that exploratory research is appropriate if the literature review demonstrates "that little or no work has been done on the group, process or activity under consideration" (Stebbins, 2001). While exploratory studies are conducted "to gain familiarity with a phenomenon or to achieve new insights into it", descriptive studies aim "to portray accurately the characteristics of an individual, group or a situation" (Kothari, 2004). Qualitative studies help in gaining a detailed understanding of a phenomenon in terms of the meanings people bring to it and are particularly useful in describing the natural settings in which it occurs (Anderson, 2010; Creswell, 2013; Denzin & Lincoln, 2011).

Literature review

We began with a review of literature to understand what is currently known about home healthcare in India and the different stakeholders. Annual reports, policy documents, research papers, newspaper articles and online media articles were included in the review.

A combination of keywords was used to search the papers published in peer-reviewed journals on Google Scholar. The search terms used were 'India', 'home-based care', 'home healthcare', 'home care', 'elderly', 'mental illness', 'disability', 'palliative care' and 'non-communicable diseases'.

The documents and reports published by the Union Government and its related ministries/institutions such as the Ministry of Social Justice and Empowerment (MSJE), Ministry of Skill Development and Entrepreneurship (MSDE), National Skill Development Corporation (NSDC) etc., legislations promulgated by the Government of India, annual reports and programme updates published by state governments, non-profit organisations, professional bodies and home healthcare companies, were reviewed.

Literature published on home healthcare in India is limited to specific programmes and interventions of government and non-profit organisations. The focus has been on

community-based outreach services for maternal and newborn care, palliative care for cancer patients and the terminally ill and geriatric care. However, there is lack of information about other providers and organisations that are engaged in home healthcare, particularly the new and emerging private, for-profit, home healthcare companies. Therefore, to understand about other providers and their service delivery mechanism, interviews were conducted with different stakeholders. For this purpose, operational definitions of 'home', 'healthcare services', 'providers' and 'organisations engaged in home healthcare' were formulated.

Operational definitions

The operational terms based on literature review, team discussions and study objectives were defined as follows:

Home: A 'household' where a group of persons live together and take their meals from a common kitchen, unless the exigencies of work prevent any of them from doing so. Persons in a household may or may not be related by blood, marriage or adoption to one another *(Census of India, 2011 and National Sample Survey, 2001).* The residential/institutional care homes, community living arrangements such as old age homes, rehabilitation centres, day-care centres etc., were excluded.

<u>Healthcare services</u>: Services under the western system of medicine, which comprise intensive care, rehabilitation care, palliative care, post-surgical/post-hospitalisation care and COVID-19 care utilised by persons belonging to any age group; services for conditions such as cardiovascular diseases, respiratory diseases, renal conditions, cancer, musculoskeletal conditions, neurological conditions, persons with long-term physical, mental, intellectual or sensory disability, old age-related health conditions and bedridden patients, among others. Assistance with daily living activities, telemedicine, investigation, diagnostic services when provided by themselves were excluded from the scope of the study.

Providers: Individuals, who work independently or through organisations that provide home healthcare; may be working in the public or private for-profit or non-profit sector; could be unlicensed personnel such as home health aides, or licensed providers registered with professional councils/commissions such as nurses and doctors. Providers do not include household members, hired help mainly assisting with activities of daily living, and community-based health workers/volunteers who make home visits as part of outreach activities or community-based programmes.

<u>Organisations engaged in home healthcare:</u> Organisations that provide home healthcare and/or train personnel who provide these services, such as private home healthcare companies, non-profit organisations, hospitals, nursing bureaus and training institutions.

Details of labour laws, insurance coverage and the accreditation process for home healthcare services were not covered in the study.

Participants and setting

A combination of purposive and snowball sampling was used to recruit respondents from home healthcare companies, non-profit organisations, hospitals, nursing bureaus and training institutions. The sampling procedure helped in selecting respondents who could provide diverse and in-depth information (Sandelowski, 2000; Wu et al., 2016). Based on the literature review, home healthcare companies, non-profit organisations, nursing bureaus and training institutions operating in the Delhi National Capital Region (NCR) were identified. Emails were sent to these organisations explaining the objective and purpose of the study and followed up over the phone. In addition, hospitals registered under the Delhi Nursing Homes Registration Act, 1953 and situated in Vasant Kunj, Vasant Vihar and Vikaspuri were contacted.

Social media appeals were shared through Twitter, Facebook, LinkedIn and WhatsApp, to identify respondents, particularly patients and individual providers. Further, respondents were identified through snowballing by requesting the enrolled participants to introduce researchers to their contacts who matched the study criteria. Interviews were scheduled based on the respondents' convenience.

In a qualitative study, a sample size of 20 to 30 respondents is typically considered adequate, but there is inconclusive evidence in literature on the ideal sample size (*Hunter et al., 2018; Vasileiou et al., 2018*). The final sample consisted of 27 respondents (18 females and 9 males). These comprised patients or their family members (n=4), providers (n=8, including three nurses and a nursing aide, physiotherapist, palliative care doctor, counsellor and nursing head), representatives of organisations engaged in delivering home healthcare (n=11), representatives of institutions involved in vocational training (n=3) and a representative of an accreditation body that certifies home healthcare companies in India (n=1). (*Please see Annexure I for respondents' characteristics*).

Data collection

Data collection was undertaken between February and May 2022 using semi-structured interview guides. Four semi-structured interview guides were developed – one each for patients or their family members, providers, representatives of home healthcare organisations and institutions engaged in training. Each interview guide was divided into three sections to enquire about: (i) the scope of healthcare services provided at home, (ii) the profile of healthcare providers, and (iii) the interaction between patients, providers and organisations engaged in home healthcare. The section on the scope of home healthcare services enquired about the health conditions for which services are provided at home; the profile of healthcare providers covered the characteristics of providers, their training and employment opportunities; the third section focussed on the hiring of home healthcare providers, description of their role and responsibilities, remuneration, and other benefits, how services are delivered at home, safety of patients and providers, financing of home healthcare services and the role of government policies and regulations in home healthcare.

Prior to designing the study tools, the researchers held discussions with persons who were involved in the home healthcare sector in different capacities. These were a former CEO of a home healthcare company, a provider (untrained aide), a professor at a government medical college involved in developing home health aide training courses and an administrator at a private hospital. The discussions helped in identifying the issues to be probed during the interviews. (*Please see Annexure II for the interview guides used in the study.*)

In-depth interviews with 24 respondents and an expert consultation with three respondents were conducted. Of the 24 interviews, 18 were conducted in-person, five over telephone, and one respondent shared written responses. The interviews and the expert consultation were audio-recorded with the respondents' permission. Two respondents did not permit audio recording, in which case handwritten notes were taken. In some cases, the respondents preferred that the interview guides be shared with them before the interview. The study team also visited the homes of four users of home healthcare services. Most of the respondents were based in Delhi NCR while three were based in Chennai, Bengaluru and Kochi. (*Please see Annexure I for respondents' characteristics*)

The duration of the interviews ranged from a minimum of 7 minutes 24 seconds to a maximum of 2 hours 24 minutes 39 seconds. The interviews with two respondents were conducted over two sessions as per their availability and convenience.

The study was conducted by two researchers, both with postgraduate education and training in qualitative research. Both the researchers had prior experience in conducting qualitative studies and were supervised by an advisor with experience in public health research. One of the researchers interviewed the respondents (PG: principal investigator), while the other took notes and recorded the conversations (SR: coprincipal investigator). Throughout the data collection process, the researchers held regular meetings to review transcripts, reflect upon them, and discuss areas to probe in subsequent interviews. The researchers had no prior relationship with the respondents.

Data analysis

Hunter et al (2019) recommend using thematic analysis as a method of choice in the exploratory descriptive qualitative approach since the aim of the study is to "explore and describe the experiences of respondents in relation to phenomena under study" (Hunter et al., 2019). The 'Framework Method' of analysis was used, which is an "inherently comparative form of thematic analysis which employs an organized structure of inductively and deductively derived themes (i.e., framework)" and is the most commonly used form of thematic analysis of interview transcripts (Gale et al., 2013; Goldsmith, 2021). The data analysis was conducted following the steps proposed by Gale et al (2013): transcription, familiarisation with the interview, coding, developing and applying the analytical framework and charting data into the framework matrix (Gale et al., 2013).

Stage 1: Transcription: Of the 21 audio recordings, 17 were transcribed by the researchers themselves, either with the help of a transcription software (Otter.ai) or manually. Four audio recordings were transcribed by external agencies. Two of these recordings were in Tamil and Hindi, while two were a mix of Hindi and English. The online expert consultation was transcribed by the researchers.

Stage 2: Familiarisation with the interview: The researchers conducted the interviews, spent time listening to the audio recordings and transcribed them, which helped in the familiarisation process.

Stage 3: Coding: The researchers coded the transcripts using NVIVO, a qualitative data analysis tool. The first set of codes (with their description) was generated jointly by both the researchers by coding the transcript of the longest interview together.

Stages 4 and 5: Developing and applying the analytical framework: Using the jointly prepared code list, both researchers independently coded a common transcript and compared the coding. They then collectively developed a series of descriptive codes to be applied to all the subsequent transcripts, after discussion and reflection on their initial coding set. The remaining transcripts were divided between the two researchers and coded independently; new codes were generated, which were tracked and highlighted in a unique google sheet accessible to both researchers and all the codes were reconciled. All the coded transcripts were merged in one project using NVIVO and a code-wise summary report was generated.

Stage 6: Charting data into the framework matrix: The researchers reviewed all the descriptive codes, the code-wise summary report and excerpts from the transcripts, looking for patterns between and within codes. Through a combination of independent review by both the researchers, followed by reflection and discussion on descriptive codes and the code-wise summary, codes were placed under tentative categories. The researchers' knowledge of the literature and notes from interviews further informed these discussions. Where necessary, additional desk research was conducted to learn more about the information shared by the respondents. This led to the development of themes and sub-themes, which were used to form the report outline. The report was written by the two researchers and reviewed by the advisor.

Eight themes were derived from the data to explain how healthcare services are provided at home. The themes and sub-themes derived to answer the research questions are listed in the table below, followed by a detailed discussion on each in the 'Findings' section.

Theme	Sub-theme
Combination of assistance with daily	Activities of daily living along with routine
living activities and medical care is	nursing procedures are the most common
provided at home.	services.
	• Specialised services: Intensive care, dialysis,
	palliative care, physiotherapy, COVID-19.
	Education and counselling.
User group is expanding.	Elderly is a significant group among home
	healthcare users.
	Post-hospitalisation patients are increasingly
	using home healthcare services.
There are five categories of providers:	Untrained aides are fulfilling the growing demand
family members, community-based	for services at a lower cost and typically assist
outreach workers, untrained aides, trained caregivers, and professionally	with activities of daily living.
qualified healthcare workers.	• Trained caregivers who have undergone vocational training are a growing set of providers
quantica ficataleare workers.	in home healthcare.
	 Nurses and physiotherapists are most common
	among the professionally qualified healthcare
	workers.
Non-profit organisations, hospitals,	Organisations are inclined towards engaging
home healthcare companies and	providers temporarily on a 'need' basis and hiring
nursing bureaus provide home	fewer staff on-rolls.
healthcare services.	Home healthcare organisations have developed
	in-house processes to provide services at home.
	Written contract or verbal understanding – DO's
	and DON'Ts.
	Continuum of care between the home and treating physician
	treating physician.On-site and/or off-site supervision of providers at
	predetermined intervals or as per need.
Financing of home healthcare services.	Cost of care is influenced by the type of provider
I maneing or nome neutricare services.	and organisation.
	Need for insurance coverage expressed.
Regulation of home healthcare	The Maintenance and Welfare of Parents and
services.	Senior Citizens (Amendment) Bill, 2019, may be
	the first step towards regulating home healthcare.
	• In the absence of any standards and regulation,
	some organisations have opted for accreditation.
Challenges in home healthcare.	Availability of appropriate and adequate
	providers.
	Travel and logistics challenges. Soft a live it and logistic challenges.
	Safety, dignity and respect of providers. Limited resources at home could limit.
	• Limited resources at home could limit interventions.
	Management of biomedical waste.
Opportunities in home healthcare.	 Management of biomedical waste. Demand and availability of home healthcare
opportumees in nome nearmeare.	services has increased manifold in the last ten
	years.
	 During the COVID-19 pandemic, home healthcare
	expanded as an alternative to hospital care.
	r rest of the second

Ethical considerations

The study proposal was presented to the institutional ethics committee of Health Systems Transformation Platform (HSTP). It was revised based on the Committee's observations and comments and the revised proposal was approved by the Committee. Verbal consent of the respondents was taken before commencing the interviews. The participant information sheet (English/Hindi versions) signed by the principal investigator was shared with all the respondents. They were assured of confidentiality and were free to withdraw from the study at any time. No incentives were offered to participate in the study. The audio files were stored in the researchers' official laptops and were password-protected. All the respondents were allotted a unique ID to maintain anonymity.

Challenges in data collection and analysis

One of the key challenges was the identification and enrolment of respondents. While some people declined to participate forthwith, some wanted monetary compensation in exchange for their time. A few agreed after repeated follow-ups. The researchers contacted some respondents using professional networks to facilitate access. Overall, the process was time-consuming. Data collection was delayed due to the third wave of COVID-19 in January 2022. Restrictions imposed during that period and the preoccupation of healthcare providers and organisations with meeting the healthcare needs at that time caused the delay.

To prevent researcher bias during analysis—the tendency to only incorporate data that the researcher deems to be important—both the researchers discussed and debated extensively while conducting the analysis. They ensured that their interpretation of the data highlighted the respondents' stories. They made a conscious effort to ensure that the analysis took into account not only the dominant view but also any contradictory/divergent views expressed by the respondents. It was indeed a challenge to ensure that the voices of all respondent groups were reflected in the findings and not overpowered by one particular respondent or group.

HOME HEALTHCARE SERVICES

A combination of assistance with daily living activities and medical care is provided at home, with the range of services increasingly expanding. From being largely restricted to assistance with activities of daily living (ADL)¹ and instrumental activities of daily living (IADL)² until about a decade ago, services at home are expanding to include advanced medical care. The increasing population of the elderly and growing burden of chronic diseases have led to a rise in the demand for healthcare services at home. Better spending capacity among a section of the population and improved clinical care at home due to technological advancements have contributed to the expansion of the basket of services. The manager of a home healthcare company observed, "Back when I was working for other organisations, home healthcare used to be assisted living in terms of ADL services such as support in bathing, walking or physiotherapy services. But in the last eight to ten years, I have realised that clinical services are now possible at home." The provision of medical care at home rose notably in the wake of the COVID-19 pandemic.

Activities of daily living along with routine nursing procedures are the most common services.

ADL is used as an indicator of people's ability to care for themselves independently. The elderly population (60 years and above) and older adults (aged 45–59 years) are more likely to have one or more ADL and IADL related difficulties, according to the Longitudinal Ageing Study in India (LASI, 2017–2018). About 24 percent of the elderly reported having at least one ADL limitation, while almost half (48 percent) had at least one IADL limitation. About 9 percent of older adults had at least one ADL limitation and 36 percent had at least one IADL limitation (MoHFW, 2020). The manager at a non-profit organisation shared that a baseline survey conducted to ascertain the need for services before starting a home care programme had revealed a demand for ADL services from the elderly population, categorised into active, bedridden, and not-so-dependent elderly.

1 /

¹ Assistance with activities of daily living refers to assistance in routine self-care activities such as support in movement in bed, changing position from sitting to standing, walking, feeding, bathing, dressing, grooming, personal hygiene, etc. *Longitudinal Ageing Study in India (LASI) Wave 1, 2017-18, India Report*

² Assistance with instrumental activities of daily living (IADL) refers to tasks which are necessary for independent functioning in the community and are not necessarily related to the fundamental functioning of a person, such as cooking, shopping, making a telephone call, taking medications, paying bills, getting around places, using web servers or applications. *Longitudinal Ageing Study in India (LASI) Wave 1, 2017-18, India Report*

Thus, assistance with bathing, brushing, walking, movement in bed, changing position and social interactions are commonly provided services at home. These are often accompanied by routine nursing care, depending on the patient's need. Routine nursing care includes monitoring of vitals such as blood pressure, pulse rate, blood sugar levels, temperature, oxygen saturation; dressing of wounds and bedsores; intravenous or intramuscular injections, such as injections of vitamin D, vitamin B12, blood thinners, painkillers, injections during pregnancy, dexamethasone injections for allergy etc., and nutrition management through total parenteral nutrition. A nursing aide shared, "If it is low sugar, we can give something like juices. As we keep watching them for 24 hours, we will be monitoring if the blood sugar level drops or shoots up."

Specialised services: intensive care, dialysis, palliative care, physiotherapy, COVID care

The nursing head at a home healthcare company observed that, "Previously, people used to hire only for ADL care. People used to fear that if the critical patient is taken home, who will manage and how?" That, however, is changing. There is rising provision of post-hospitalisation intensive care and monitoring and stabilisation services at home. A hospital-like ICU environment at home with equipment such as ICU beds, ventilator support, cardiac monitor, BiPAP, suction machine, etc., are among the intensive care services provided at home. The head of a hospital's home care programme shared, "Nowadays, people demand ICU set ups at home. ICU at home is the prime focus in home healthcare. When nurses are trained in ICU services, they can provide all types of services." One home healthcare company reported offering ICU type of services in about 225 homes in different locations across the country on the day of the interview.

The commonly performed specialised procedures at home are plastic surgery dressing or specialised dressing; Ryle's tube insertion or nasogastric tube insertion; fluid management through IV drips, cannula insertion; Foley's tube insertion or catheterisation; total parenteral nutrition; tracheostomy; dialysis – both haemodialysis and peritoneal dialysis (*Jha*, 2019) and stoma care. Sample collection for laboratory tests and radiology services such as X-rays, ECGs and Holter monitoring are also provided at home.

Palliative care at home comprises symptomatic management of serious health conditions such as cancer, stroke, congenital anomalies, neurological conditions, spinal cord trauma and other such conditions. It includes relief from side effects of cancer treatment and follow-up post-chemotherapy. Chemotherapy at home comprises services like peripherally inserted central catheter dressing, blood transfusion, chemo port flush, adjuvant therapy administration, neutropenic care, parenteral nutrition and electrolyte/antibiotic infusion. The non-profit organisation covered in the study, which delivers palliative care at home, supports the patients in accessing free or subsidised drugs and equipment such as artificial limbs, prosthetic arms and legs, compression garments, belts, wheelchairs, and crutches. It also offers education and counselling to patients and their family members as they may get stressed. They are educated about

managing common conditions among patients living with cancer, for example, how to care for wounds, vomiting, loss of appetite, mouth hygiene, overall hygiene, medicine administration etc. A counsellor said, "If the patient starts having bleeding, then the caregiver gets stressed, so we tell the caregiver how to deal with such a situation. We give them this reassurance that if you have any problem at any time, don't panic, you can call us." Similarly, a nurse said, "In the initial days I put colostomy bag, I'll show the first time how to put it, then the patients do on their own. If they face any problem, then they call us and we go and check."

One service that is extensively used at home is physiotherapy for conditions such as back pain, neck pain, sports injuries, post-operative cases, geriatric cases, etc. The easy availability of physiotherapists, ease of contacting them, growing user awareness and rise in surgeries by private hospitals were reported to be the contributing factors. A physiotherapist observed, "More the number of private hospitals will be there...more surgeries are out there, and more surgeries they do, better it is for physiotherapy part." The nursing head at a home healthcare company reported that their "physiotherapist is also doing well because every stroke patient needs physiotherapy, and every pulmonology patient needs a chest physiotherapist."

During the COVID-19 pandemic, home healthcare received a lot of attention. Teleconsultation, routine nursing services, patient education, doctor-on-call, nutritionist-on-call, assistance during emergency, prevention kits (for patients and caregivers, masks, sanitizer, wipes etc.), digital thermometer, SpO2 probe, medication were provided to manage asymptomatic and mildly symptomatic COVID-19 cases at home.

Duration of healthcare services at home

The patient's condition typically dictates the duration of home healthcare services. Home healthcare services are provided for both short-term duration, such as repetitive wound dressing or frequent injections (twice or three times daily), and longer-term duration, which can last for several weeks, months, or even years.

Patients who need long-term home healthcare are those with paralysis, accident cases, fracture cases, patients with Alzheimer's disease, dementia, brain haemorrhage, bedridden patients or the geriatric population.

HOME HEALTHCARE USERS

Home healthcare services are used by people with acute or long-term physical, mental, intellectual or sensory impairment; bedridden or dependent patients; post-hospitalisation or post-operative cases; patients with musculoskeletal conditions such as arthritis; the elderly; pregnant women; new mothers and newborn children. People with mental health conditions such as dementia, Alzheimer's disease or mental illnesses are also among the users of home healthcare services. During the pandemic, people with COVID-19 were the key users of home healthcare services. The categories of people who use home healthcare services is expanding, the two most common ones are discussed below.

Elderly is a significant group among home healthcare users

Healthcare services at home are in high demand for the elderly population who mostly require ADL and IADL assistance. There will be more than 319 million elderly (above 60 years) by 2050, growing at a rate of 3 percent annually (MoHFW, 2020). The manager of a home healthcare company shared that, "In general, as a home healthcare industry, it is like 80:20, where 80 percent of services are consumed by elders (more than 50 years old) and 20 percent services are consumed by those less than 50 years." In fact, demand for geriatric care is driving healthcare organisations to hire providers specifically to meet the needs of the elderly. The head of a hospital's home care programme informed that they have been recruiting more general duty assistants (GDAs) to cater to the elderly patients who do not have any serious health conditions. The elderly who lack family support also seek such services. As the manager of a home healthcare company said, "It happens in NRI (non-resident Indian) cases a lot, where the elder otherwise is okay and mobile but still the family wants support, mainly to bring medicines, doctor consultation, or take to the hospital." As such, healthcare services for the elderly with conditions such as dementia, Alzheimer's disease or Parkinson's disease are scarce in India (Sinha et al., 2020; Shajahan, 2022).

Post-hospitalisation patients are increasingly using home healthcare services

Apart from the elderly, the other significant users of home healthcare are patients who need follow-up care and monitoring after discharge from the hospital. These comprise patients in need of intensive care; patients recovering from stroke, kidney failure, brain haemorrhage, lung infection, accidents, fall, fracture, knee replacement surgery, hip replacement surgery etc. In an analysis of its patients, the home healthcare company,

Health Care at Home, reported that nearly one-third (36.89 percent) patients belonged to the critical care category, having been referred post-hospitalisation for ICU or palliative or post-surgical care at home (Singh et al., 2019). Patients suffering from non-communicable diseases such as diabetes; hypertension; people living with cancer of the lung, breasts, colon, oesophagus, and oral cancer (tongue, buccal mucosa), multiple myeloma, or end-of-life patients and those suffering from the side effects of chemotherapy and radiotherapy are also among the users of healthcare services at home. Other conditions for which people seek home healthcare are pregnancy, obesity, comorbidities, and sleep disorders.

Information among users about home healthcare services

The most common means by which people learn about home healthcare services is through word-of-mouth. For instance, the daughter of a geriatric patient shared that her colleague recommended an organisation for her ageing mother. A nursing aide who works independently as well as through organisations informed that, "A relative of the same patient, one who'd had an open heart surgery...without contacting the agency, the same person referred me for that." The providers, both individuals and organisations, therefore reported that they make a conscious effort to ensure that their users are happy and satisfied with their services.

The hospital staff recommend a provider or an organisation to the patient at the time of discharge, depending on the patient's need. Almost all organisations liaison with hospitals and seek patients in need of home healthcare. A nursing aide said, "When they get discharged from the hospital...homecare people have given their visiting cards to everyone. One with the reception, another with the nurses, and another with the housekeeping people. When they do their rounds and cleaning, they tell them." Some organisations have established their help desks inside hospitals. For example, the non-profit organisation, that was part of the study, has links with both public and private hospitals in Delhi.

Some hospitals who have their own home care services, such as Max Hospital, Apollo Hospital and Sir Ganga Ram Hospital, meet their patients' needs themselves (Kandhari, 2018). The head of a hospital's home care programme said, "The treating doctor, nurse tell the patient about home healthcare team. Our team also does their own rounds to identify any such patients. The home healthcare team gets referral from departments like neuro, ortho, ICU for long term care." A respondent shared that some such hospitals do not permit their patients to use anyone else's services.

Walk-in enquiries at hospitals are another mode by which patients contact providers. A nurse who provides services at home independently while being employed full-time in a hospital shared, "Someone came to the hospital earlier and called. I went to two places like that, through their contacts I am called. I have been doing home visits for last eight years. Sometimes doctors also send. In morning I go before coming to hospital and in evening after

hospital duty. I can't give longer duration services at home (e.g., bedridden patient, has bed sores) as I work in the hospital."

The websites of some organisations provide information about their range of services, locations where they serve, approximate cost and contact information. One can also call on the helpline numbers mentioned on the websites. Online portals (online business directories) such as Just Dial, Sulekha India, etc., which maintain databases of organisations providing different kinds of services are another source of information. Online health aggregator platforms such as Practo, CallHealth, mfine, etc., offer information about providers and link them to the users.

A respondent informed that the Ministry of Skill Development and Entrepreneurship (MSDE) is considering developing a web portal with the contact information of trained caregivers. This will help anyone in need to directly contact the caregivers and seek their services.

HOME HEALTHCARE PROVIDERS

The providers of home healthcare in India can be broadly divided into five categories – family members, community-based outreach workers, untrained aides, trained caregivers and professionally qualified healthcare workers.

Family members are most often the first to care for sick or incapacitated persons at home. Evidence indicates that similar to the social and cultural expectations globally, caring for the sick is traditionally believed to be women's duty within the family in India too. In a study conducted to assess the profile of home-based caregivers of bedridden patients in North India, family members accounted for about 82 percent (250/305) of those caring for bedridden patients³ at home and women made up 55 percent of all caregivers; mostly wives, daughters-in-law and female hired help (*Bains & Minhas, 2011*). Some nongovernment organisations and hospitals offer training programmes for family members to improve their knowledge and skills so that they can provide simple rehabilitation care for stroke patients, those suffering from schizophrenia or dementia or for children with mental retardation, etc., at home (*Vimala, 2013; Balasubramanian et al., 2017; Lindley et al., 2017; Halemani et al., 2021*).

Community-based outreach workers, also known as community health workers, are another type of service provider, who deliver services at home as part of government and non-government programmes for specific population groups such as pregnant women, newborn children, geriatric population, cancer patients etc. The Accredited Social Health Activists (ASHAs) working under the Government of India's National Health Mission (NHM) is one such example. The community-based outreach workers live among the people they serve, are members of the same community, receive training to perform their roles in accordance with the specific programme and are typically paid with a fixed honorarium or task-based incentive (Dias et al., 2008; Janardhana et al., 2015; Kalkonde et al., 2019; NHM, 2019). In states such as Kerala, Manipur and Telangana, community health workers identify families who require palliative care and refer them to the nearby government health facility as a part of the National Program for Palliative Care (Kumar, 2013; Philip et al., 2019; NHM, 2019).

Family members and community-based outreach workers were not the focus of the study. It examined the roles of the other three categories of providers – untrained aides, trained caregivers and professionally qualified healthcare workers. These providers may

³ Bedridden patients: The study defines them as 'people confined to bed for 15 days or more, for 90 percent of the time during the day and unable to get out of bed without assistance' (Bains & Minhas, 2011).

offer services independently, that is, hired directly by patients, or through organisations such as hospitals, home healthcare companies, non-profit organisations and nursing bureaus. The study revealed that untrained aides and trained caregivers who have undergone vocational training are the most common providers of home healthcare services.

Untrained aides are fulfilling the growing demand for services at a lower cost and typically assist with activities of daily living.

Families may not always be able to provide the required care by themselves and need external support depending on the patient's condition and needs. Families frequently hire untrained aides, full-time or part-time, mostly to help with ADL and IADL. Such aides provide services in shifts ranging from 3 to 12 hours during the day, 12-hour night shifts, or 24 hours stay-at-home, ranging from a few days to a few months as per the patient's need. They are commonly referred to as aides, attendants or *ayahs*, usually lack formal training in assisted living and learn with experience. The study mentioned above that assessed the profile of home-based caregivers of bedridden patients in North India, found that none of the 55 hired help for home care of bedridden patients had received any formal training in care provision. Instead, they had learnt on the job under the supervision of family members (*Bains & Minhas, 2011*).

One reason for the high demand for untrained aides is that their services cost lesser than those of the trained or professionally qualified healthcare providers, such as nurses. To meet the demand for such aides, some organisations impart a few days of orientation training to them. The head of a hospital's home care programme stated, "Ayahs provide child support, ADL support to young mothers and pregnant women, and take care of hygiene but are not educated and do not provide medicines. They are trained in the maternity ward about care of the umbilical cord, breastfeeding, breast care, perineal care." In some cases, families request that the untrained aide administer routine nursing care such as injections. The head of a nursing bureau clarified, "Yes, helpers are not trained. I teach them, in fact. I give them basic training like how to sponge a patient, how to lift a patient, change their clothes, take them to the toilet, feed them, that's all without medicines." When families request for injections, "I say sorry I will not let her poke you, because tomorrow if the patient gets an abscess, you're going to blame me." Thus, though they are not permitted to give any form of nursing care, some of them eventually pick up skills like monitoring vital signs and may even administer injections.

Trained caregivers who have undergone vocational training are a growing set of providers in home healthcare

The home healthcare sector is witnessing an increase in the number of trained caregivers who undergo vocational training and are skilled to deliver patient care and assistance with daily living activities. They are commonly referred to as home health aides (HHA), geriatric care aides, general duty assistants (GDA), geriatric care assistants, GDA

Advanced, nursing assistants or nursing aides, among others. They cater only to the patient's needs and do not perform any household work. The person in charge of a vocational training course stated that these aides are skilled to provide services such as "bathing care, social care, nail cutting, cleaning sores/wounds for which training is required" in contrast to untrained aides who work without any training. "GDAs are medically trained and certified, they monitor blood pressure, check blood sugar, measure intake-output, give insulin injections and medication, but are not trained for other injectables," said the head of a hospital's home care programme. They are not trained to perform surgical dressing, oxygen administration, catheterisation, Ryle's tube insertion, tracheostomy care, gastrostomy care and handling of patients on ventilators, in-emergency or in need of critical care.

The vocational training courses are designed to generate an employable cadre to meet the growing demand of groups such as the elderly and persons with disabilities. The Ministries of Social Justice and Empowerment (MSJE), Skill Development and Entrepreneurship (MSDE), and Health and Family Welfare (MoHFW) of the Government of India, offer courses of similar nature through their respective institutes. The curricula are comparable across ministries though there is variation in the eligibility criteria and course duration. Additionally, the state governments, state medical universities and private organisations (for-profit and not-for-profit) also conduct such vocational courses with different eligibility requirements and course duration. The private organisations may not necessarily be affiliated with or recognised by the government. (*Please see Annexure III and IV for details on vocational courses and the skills they impart to the different categories of trained caregivers*).

These vocational training courses cannot be equated with the formal qualification of a diploma or degree granted by a university. The trained caregivers are therefore not registered with a professional council. The manager of a home healthcare organisation observed, "Jaise MCI hai, Medical Council of India, waise GDA ki koi council nahi hai alag se (like there is MCI, Medical Council of India, there is no separate council of GDA)." Drawing a parallel between trained caregivers and healthcare providers like medical laboratory technicians, he stated, "It is like DMLT (Diploma in Medical Laboratory Technology), when someone does DMLT, they do not get a registration number, they can just go and start working in a lab...waise hi iska bhi hai, iski koi regulating body nahi hai (similarly GDAs do not have a regulating body)."

There is an increasing awareness and demand among patients and families for trained caregivers to assist with ADL, though their services cost more than the untrained aides. In fact, the trained caregivers are more in demand than professionally qualified providers. The manager of a training institution-cum-home healthcare company observed that there are "...more of geriatric attendants than nurses. So, I would put it as, you know, 80:20, or maybe even 85:15, 85 towards geriatric attendants, and only 15 of them would be nurses." The head of the nursing bureau informed that on the day of the

interview, around 40 attendants and 30 nurses were deployed through her bureau. Similarly, the manager of a home healthcare company stated that "It is a 2:1 ratio, 2 is ADL related support provided by GDAs at home and 1 is nursing care for continuous monitoring of the patient by the nurse to check over their nebulizers, BiPap machines or perform regular suction."

Nurses and physiotherapists are most common among professionally qualified healthcare workers

Healthcare workers recognised in the modern system of medicine, such as doctors, nurses, physiotherapists and other health professionals provide healthcare services at home. They are professionally qualified, trained, licensed and often registered with their respective professional councils or commissions. "We hire doctors, nurses and phlebotomists from a pool of experienced talent," said the co-founder of a home healthcare company. Of these, nurses and physiotherapists are the most common providers at home.

Nurses (ANMs, GNMs, B.Sc. Nursing and Post B.Sc. Nursing), provide routine nursing services and specialised services like critical care, cardiac care, geriatric care and palliative care at home. The nursing head at a home healthcare company described the key tasks of nurses as, "Critical care and normal nursing care services such as suctioning, *IV injections (some need to be put on drip), normal tracheostomy, BiPap with tracheostomy,* Ryle's tube, giving medication, etc. They also provide services to bedridden patients, and 24x7 nursing service." Home healthcare organisations favour hiring nurses with experience of working in hospitals to reduce the need for training. However, some organisations conduct in-house training depending on the nurses' prior experience and skills. Regarding whether there are more male or female nurses employed in the home healthcare sector, the respondents had contradictory opinions. However, two studies conducted in Bengaluru, Delhi and Mumbai found an almost equal proportion, with female nurses being slightly more than male nurses - 52.4 percent and 51.3 percent females and 47.6 and 48.7 percent males, respectively (Singh et al., 2020; Singh & Chaudhari, 2020). Further, the interviews revealed that some nurses engaged in home healthcare were not registered with any nursing council because the institutions where they studied were not recognised. Such nurses lack opportunities for career progression and may be laid off by home healthcare organisations when they undergo accreditation, as was shared by a respondent.

Allied healthcare professionals such as physiotherapists (B.Sc. and M.Sc. in Physiotherapy), nutritionists, dietitians, counsellors and radiographers are also engaged in providing services at home. Physiotherapists are the most common in this category. A physiotherapist who practices independently shared that he does not like to be associated with any home healthcare organisation, "because we will go to some company, they will charge XYZ amount from us, then you know we do not have a direct thing and there are too many hassles like fill this paper, fill that paper, unnecessarily, there's no point."

Though occupational therapists and respiratory therapists are mentioned as providers on websites of some home healthcare companies, none of the respondents in the study alluded to them.

Doctors—MBBS graduates, as well as specialists like nephrologists, pulmonologists, palliative care specialists, critical care specialists, among others—provide services at homes. They examine the patient, review previous medical records if any, and prescribe diagnostic tests and treatment. Patients who need geriatric care, palliative care and those who are immobile/bedridden or near the end of their lives, benefit most from doctors' services at home. "For me, the biggest factor is moral support and the relief that there's somebody who's here; professionals coming and seeing is very different," remarked the daughter of a geriatric patient regarding a doctor visiting her elderly mother at home. However, arranging the services of a doctor at home is difficult and expensive.

ORGANISATIONS ENGAGED IN HOME HEALTHCARE

Non-profit organisations, hospitals, home healthcare companies and nursing bureaus provide home healthcare services ranging from basic to complex care, such as assistance with activities of daily living, nursing care, physiotherapy, critical care etc.

Non-profit organisations: Home healthcare services have been offered by non-profit organisations for more than 20 years in India. Their focus has mostly been on palliative care for cancer, geriatric care and on bedridden/dependent patients who cannot make frequent hospital visits or are too sick to care for themselves. For instance, CanSupport has been providing palliative care through home visits to cancer patients who are too sick to travel to the hospital for about 25 years,⁴ HelpAge India offers palliative care to end-stage cancer patients in collaboration with various cancer hospitals and organisations,⁵ Pallium India offers home care to people who cannot access healthcare facilities because they are bed-bound, elderly, live alone with no one to accompany them or are geographically isolated.⁶

Hospitals: Several hospitals, especially private corporate hospitals, have started their own home healthcare departments to mainly tend to patients discharged from their hospital. Over time, some of these departments have developed into standalone businesses, like Apollo Home Care and Max@home. On the other hand, Sir Ganga Ram Hospital's 'Reach Out' programme continues to run as the hospital's in-house home healthcare department. In India, public health facilities in most states do not offer home healthcare services, except a few such as Telangana and Kerala (Jayalakshmi & Suhita, 2017; Gopal, 2022).

Home healthcare companies: Private, for-profit home healthcare companies have gained prominence in India in the last decade. They offer a variety of services in collaboration with hospitals, diagnostic centres and other vendors. While some companies cater to specific groups, such as the elderly or patients in need of intensive care, others provide services to a wide range of people. These could be the elderly, people with diabetes, heart disease, stroke and post-operative or post-hospitalisation cases, among others. Portea Medical, HCAH, Critical Care Unified, Care24 and EMOHA Eldercare are some such companies, mostly operating in tier-1 cities and to some extent in tier-2 cities; some function in multiple locations, while others have operations in only one location. Home healthcare companies primarily offer services in the form of service packages from which

⁴CanSupport: https://cansupport.org/about/
⁵ HelpAge: https://www.helpageindia.org/

⁶ Pallium India: https://palliumindia.org/

users can select depending on their need. During the COVID-19 pandemic, home healthcare companies offered home isolation packages of 14 days, mostly for patients who were pre-symptomatic or had mild COVID-19 symptoms.

Nursing bureaus: Apart from meeting the staffing needs of hospitals, nursing bureaus send care providers to people's homes as well. They offer nurses, male/female attendants, babysitters, and in some cases, physiotherapists too.

Representatives from the non-profit organisation, hospitals, home healthcare companies and nursing bureau were interviewed to provide information on how they deliver home healthcare services. The interaction with home healthcare companies was confined to those that provide services in multiple locations. Discussed below are some key aspects of how home healthcare organisations deliver services.

Organisations are inclined towards engaging providers temporarily on need basis and hiring fewer staff on-rolls.

The organisations deliver healthcare services at home through a combination of temporary providers and on-roll staff (popularly known as permanent staff). They are more inclined towards engaging providers temporarily on a 'need basis' and hiring fewer staff on their rolls. The on-roll staff in some organisations are entitled to benefits such as fixed monthly salaries, health insurance, paid leave, provident fund etc., which the temporarily hired providers do not enjoy. The organisations, however, deduct tax from their remuneration in accordance with the Indian income tax laws. A nursing aide informed that, "Permanent nursing staff of home healthcare companies may get up to 25,000 rupees per month, which could be regardless of whether they get cases or not, whether they work for 24 hours or 12 hours and out of this ESI (Employees' State Insurance Scheme), PF (Provident Fund) etc., will be deducted. With big companies, I've heard that they have 2 days (paid) leave."

The interviews revealed that the ratio of temporary to on-roll staff in home healthcare organisations could be around 80:20. "We have, what we call as permanent staff/employees on rolls, and we have on-demand staff/on-need-basis staff," said the CEO of a home healthcare company. Of about 2,600 people associated with the organisation, only 150–200 people are on its rolls. Though some home healthcare companies began their operations with a permanent staff model, they shifted to hiring providers on-demand for reasons of sustainability, legal liability and increasing operational costs. The head of a hospital's home care programme shared, "We cannot have more staff on our rolls, then we have to follow PF, ESI, need to give paid leave etc., our charges will then increase. We have 10–15 nurses working through a vendor. We recruit them, train them and hand them over to the vendor who provides uniforms and maintains all records. The vendor takes about 10 percent commission." The manager of a home healthcare organisation reported that some providers may prefer a temporary arrangement over full-time employment as it allows

them to work with different organisations and choose patients according to their preference. However, this could not be ascertained from the providers themselves. The organisations adopt certain strategies to attract temporary providers. These include offering in-house training, regular monitoring and support, granting leave in accordance with their religious holidays, financial incentives etc.

The non-profit organisation engaged in home healthcare prefers to have providers on its payroll but faces challenges in retaining nurses and doctors as their salaries are usually not on par with the for-profit sector.

Before deploying providers to patients' homes, some organisations conduct in-house induction training, which may range from a few hours to 14 days and could even go up to three or six months. It may include classroom sessions and on-site practical training as understudies. The key objective of the induction training is to familiarise the providers with the company's standard operating procedures (SOPs) and refresh or upgrade their skills, as they would be the organisation's face to the outside world. The training is particularly important for fresh candidates who lack prior experience. The head of a hospital's home care programme mentioned that they, "train GDAs and ayahs for about 7 to 10 days before sending the staff for home healthcare services." Similar to this, the CEO of a home healthcare company stated that in case of nurses, "If I take somebody who has come fresh off the course, then they go through a three-to-six-month training. If they are experienced people, have worked in hospitals, worked in small cities, etc., their training could be much shorter, just 10–15 days on particular procedures."

Home healthcare organisations have developed in-house processes

The organisations have developed in-house processes that involve conducting the patient's medical assessment, home assessment and a written contract outlining the DO's and DON'Ts before initiating services for a new patient. These processes are similar across organisations with some variations, which are discussed below.

The first step is to conduct a medical assessment comprising the patient's present condition, medical history and specific healthcare needs. In home healthcare companies, generally, this assessment is conducted by a nursing supervisor or in some cases by the in-house doctor. In critical cases, the medical assessment is conducted to confirm whether the patient can be moved home from the hospital and provided the necessary services at home. In the case of non-profit organisations, the home care team comprising a doctor, nurse and counsellor conduct the patient's medical assessment on their first home visit.

Based on the patient's need assessment, a treatment or care plan is developed, preferably in consultation with the patient's treating doctor, especially if it is a post-discharge case. "A care plan is actually a living document because the condition of the patient can change over a period of time. So, the care plan is for what needs to be done, what's the medication,

what are the procedures, at what frequency etc.," stated the CEO of a home healthcare company. The providers deployed through the nursing bureau deliver services as advised by the patient's treating doctor or the family. The nursing bureau in-charge, who is herself a nurse, assigns a suitable person to the patient as per the patient's condition – palliative, geriatric, paralysis, dementia etc. She revealed that, "The family will get the doctor, we don't come in between and whatever the doctor needs, he will communicate with the nurse and the nurse will report to him. If the doctor says to monitor and give him the report, nurses will give it." The organisations may decide not to pursue cases where the patient's needs do not match their capacity, resources or field of expertise. For instance, the manager of a training institution-cum-home healthcare company said, "We take up only those areas where caregiving is required and don't take up areas where it goes into nursing."

Apart from medical assessment of the patient, the organisations conduct home assessment to capture information about the location of the house, its approachability, basic facilities such as a mattress, bed, chair, clean/separate washroom, facility for food in case of 12 hour or 24 hour shifts, family's food habits (vegetarian/non-vegetarian), religion, presence of male members as well as pets to accordingly match the providers with the family. "We can't send a caregiver who's vegetarian to a non-vegetarian family. In an Indian context, we can't even send a core Muslim person to a core Hindu," stated the manager of a training institution-cum-home healthcare company. If the house is located in an area that is difficult for the staff to reach or seems unsafe, organisations may refuse to provide services. As per the head of a hospital's home care programme, "There is gender consciousness; for example, for a male patient, we will send male staff. Female nurses can't manage them...if the male patient is conscious and not very old, then we don't send a female nurse. For an 80-year-old male patient, we can send a female nurse. Depending on the age and sex, we provide female nurses." However, there is no consensus on the issue. While one respondent claimed that they send male staff to treat male patients, another indicated that they frequently assign female nurses to treat male patients because they receive more requests for female nurses.

The non-profit organisation assesses the family's socioeconomic status according to the modified Kuppuswamy scale, possibly to prioritise patients for free or discounted supportive services.

Written contract or verbal understanding – DO's and DON'Ts

Taking the patient's medical condition and the home environment into account, the service package and contract are drawn up. The home healthcare companies draw up a written contract with the patient, which specifies services that would be provided, duration, payment mechanism, the provider who would be deployed and what would the provider do and not do. It also spells out expectations from the family, their responsibility towards the provider and takes their consent to use the company's services. It is explained to the families that the services of the providers are only for the patient and not for the household. "We sign a contract with the clients, in which it is clearly mentioned about the roles and duties of the caregiver," said the manager of a training institution-cum-

home healthcare company. Such expectation setting – the 'do's and don'ts', if established in the beginning, help to avoid conflict later, observed the manager of another home healthcare company.

There is no written documentation for providers working through the nursing bureau. Their communication with the patients and families is verbal, based on mutual understanding and trust. The head of the nursing bureau stated, "Families very well know what the job of a nurse is. I tell them if you want to continue, you can continue, otherwise make my payment and tomorrow the nurse will not come."

The non-profit organisation maintains each patient's file which contains the case history, family details, care plan, family's written consent and the treatment/services given during each visit.

The organisations verify the providers' educational certificate, Aadhar card and PAN card, and facilitate their police verification before deploying them at patients' homes. However, to protect themselves from legal liability, home healthcare companies include a clause in the written contract that the provider is not on their rolls and the company would not be responsible for their actions. As an additional safety measure, one respondent shared that his home healthcare company is protected under the Professional Indemnity Insurance⁷ and Fidelity Guarantee Insurance⁸.

Continuum of care between the home and treating physician

The patients who receive care at home may have linkages with a hospital or their treating physician. The provider at home may be in touch with the patient's treating physician directly or through the family and offer care accordingly. As the co-founder of a home healthcare company explained, "When patients come to us post discharge, we receive the discharge summary from the treating physician. This helps us follow the line of treatment. We also keep the treating physician in the loop and take additional inputs as required." At the same time, the patient may have no contact with the hospital/treating physician after discharge from the hospital. "So, there are a lot of cases where we like to be in touch with the treating doctor, because we give the feedback...but for a lot of cases there is no contact, because once the patient is discharged from the hospital, the whole thing is cut off," said the CEO of a home healthcare company.

The patients of the non-profit organisation that provides palliative care to people living with cancer, seek regular treatment at hospitals such as AIIMS, Safdarjung, Delhi State Cancer Institute, Max, Fortis etc. However, the home care team of the organisation has no direct contact with the patients' treating physicians in these hospitals.

7

⁷ Professional Indemnity Insurance helps the organisation if there is a suit filed against it for an act of error, malpractice, or negligence, for e.g., a medication error happens due to the provider's oversight or if a provider slept off and the patient fell from the bed.

⁸ Fidelity Guarantee Insurance safeguards the company from financial losses arising due to forgery, theft, money misappropriation, embezzlement, and other dishonest acts by employees in the home environment.

The need for referral to hospitals among elderly patients is quite common. However, home care providers are not usually involved in emergency referrals. They may gauge the need for hospitalisation and inform the family. Finally, it is the family's decision and responsibility to take the patient to the hospital. "Once or twice a week it happens that we need to do emergency evacuation," shared the manager of a home healthcare company. On the family's request, the home healthcare company may facilitate the referral by arranging for an emergency response team, ambulance and prior intimation to the hospital. These services are charged extra, over and above the routine care package. The companies usually have tie-ups with a few hospitals where they can facilitate treatment during emergencies. As the nursing head at a home healthcare company revealed, "We can call the ambulance. I talk to the (ambulance) attendant and tell him that the condition is this, and there is a need to hospitalise...take to the nearest hospital.... Or our salesperson has a tie-up with hospitals, he calls and arranges the bed."

On-site and/or off-site supervision of providers at predetermined intervals or as per need

The technical and behavioural aspects of providers, such as adherence to the treatment plan, their adjustment and overall conduct and behaviour in the home are subject to supervision by home healthcare organisations. Supervision is conducted by the supervisory staff who usually have a mix of technical and managerial skills. The supervisory staff comprises trained nurses and caregivers who have experience working as providers themselves, who understand the sector and have good people management skills. Usually, organisations promote their permanent staff to the supervisory cadre, using it as a mode of career progression within the organisation. "Sometimes, there are cases wherein very good caregivers have been promoted to supervisors as a part of their career progression. Caregivers who have been with us for, let's say, two to three years, who have good managerial skills, we generally promote them," the nursing head at a home healthcare company explained.

The supervisory staff conducts supervision through personal visits to patients' homes, phone calls, monthly coordination meetings with their staff and through patient feedback. The quality assurance executive at the non-profit organisation stated, "Koi concern jab hota hai – medical se juda hua, psycho se juda hua, ya pain kum nahi hua, toh woh hum immediately report karte hain team ko (When there is any concern – medical related, psycho [emotions] related, or pain is not reduced, then we immediately report it to the [home care] team)." The organisation has also devised a post-bereavement process to close the patient's file after death. For this, the quality assurance executive visits the family post bereavement and seeks their feedback about the support they received from the organisation using a pre-designed questionnaire.

Supervision visits may be more frequent at the beginning of the service or if the patient is in a critical condition. For example, a patient with a mental health condition such as dementia may be aggressive, and the supervisor may visit every alternate day to check

on the provider. On the other hand, if the patient has no special needs and the provider has been hired only because an elderly person is living alone, the supervisor might follow up over the phone. Supervisors also conduct home visits upon receiving complaints from the provider or the family. The head of the nursing bureau stated, "…like families will say ki ye nurse toh achi nahi hai, kuch kaam nahi aata hai (this nurse is not good, she knows nothing), I'll then go, ask the patient, ask the relative."

A non-profit organisation follows up with providers who undergo its training programme and are placed in homes to make sure that they continue in the job. Such follow-up is done for six months after placement with the understanding that if one sticks to the job for six months, then they are likely to remain in the sector.

FINANCING AND REGULATION OF HOME HEALTHCARE

The study findings reveal that while specialised services such as intensive care may be cheaper at home than in hospital, the cost of hiring a provider at home is high. Hence, only a small section of the population can afford home healthcare, thereby restricting its reach. The limited affordability is compounded by the fact that medical insurance covers home healthcare only in specific conditions as discussed below.

FINANCING OF HOME HEALTHCARE

The cost of care is influenced by the type of provider and the organisation

A trained caregiver, such as a GDA, can cost between INR 30,000 and 40,000 for 24-hour service, and around INR 18,000 for 12-hour service, per month. While the monthly cost of hiring a nurse through an organisation could be up to INR 90,000 to 1,00,000 for 24-hour service and around INR 50,000 for 12-hour service (INR 1,300-1,600 per day) (Kandhari, 2018). Physiotherapy services usually cost 30 to 40 percent more at home than at physiotherapy clinics. A doctor with an MBBS qualification may charge between INR 2,000 and 3,000 per home visit, specialists charge between INR 4,000 to 5,500 and super specialists may charge from INR 8,000 to 10,000. Usually, the cost is higher in tier-1 cities like Delhi, Mumbai, Bengaluru and tier-2 cities like Gurugram.

The for-profit organisations reportedly retain a margin of 20 to 40 percent in the services that they provide. Some home healthcare companies claim to provide premium quality services and therefore charge more than others. The cost also depends on the availability of the provider and the brand value of the company. For instance, the charges to take care of patients who are difficult to manage, such as those who are aggressive, have dementia or other mental health conditions, are higher since there are fewer providers who are skilled to attend to such patients. The charges for services taken from renowned hospitals or companies are higher on account of their brand value, which is not necessarily an indication of better quality services. "Sometimes, people are keen to use services from big hospitals and companies only because of their brand value. They get impressed that the staff wears the company's uniform with its name on it but that does not mean that the staff is well-trained," said a respondent.

The more services that a patient takes from a home healthcare company, the greater the company's business volume and profit. Therefore, along with human resources and specialised equipment like ventilators, hospital beds, etc., companies also provide

consumables such as diapers and medicines and services such as laboratory tests. As the manager of a home healthcare company said, "Since these are all private firms, everyone wants to provide as many services at home as possible so that they can maximise their profit." For example, the need for diapers is high among elderly patients and a company can earn 20–30 percent profit as it procures them in bulk at lesser cost but sells to the patient at the maximum retail price. Similarly, the company gets a margin of up to 30 percent in arranging services such as laboratory tests and X-rays through third parties. One respondent's words capture the business sentiment, "Patient ki jitni dependency hamare upar hogi, utna hi hamare liye accha hai na (the greater the patient's dependency on us, the better it is for us)."

In the present scenario, when the bulk of healthcare services at home is provided by the private, for-profit sector, their use is restricted due to high cost. Some not-for-profit organisations offer services free or at a subsidised cost. The home care programme of a hospital offers subsidy to some of its patients. The head of a hospital's home care programme said, "We also cater to patients from the lower middle class, especially when they require nursing care at home, for e.g., transplant surgery patients. We provide concessions. We have given discounts of about 90,000 rupees in January, 60,000 rupees in February and one lakh rupees in March to needy families."

Need for insurance coverage

The coverage of home healthcare services under medical insurance is confined to certain conditions in India. Services such as specialised nursing, medication, diagnostics and physiotherapy sessions are covered for 30 to 60 days, post-hospitalisation, based on the doctor's prescription. The head of the nursing bureau informed, "...the doctor has to say that you need these special services. I give you the bill for nurses, doctor signs it and then you can get it reimbursed." Disease-specific coverage is available, for example, in the case of dengue, COVID-19, chikungunya but it is usually only for 3–4 days of home care and for a limited amount. Since these services generally go on for longer, effectively they are as good as not covered.

The provision of insurance would help in expanding the reach of home healthcare services to a larger population and reduce the need for hospitalisation and readmission. One of the respondents suggested that components such as out-patient and day-care treatments, home healthcare and pre- and post-hospitalisation could be provided as separate or add-on services to the existing insurance products. Another respondent wanted the government insurance scheme, Ayushman Bharat, to include home healthcare. However, covering a service under insurance depends on its viability for the insurance company. Services like video consultation that are comparable in cost to routine consultation may be covered. On the other hand, 24x7 nursing or attendant services would be too expensive for any company to cover. A respondent felt that it is difficult to define who really needs such a service and who can be managed with family

support. The opinion of two doctors could also differ on this and therefore, perhaps, the insurance companies are keeping away from it. Another respondent warned of the pitfalls of insurance by highlighting the manifold increase in the number of neurosurgeries in the last ten years. Since many people have insurance cover, surgeries have become very common as it is a profitable venture for doctors and hospitals.

REGULATION OF HOME HEALTHCARE

One reason why some respondents advocated for home healthcare to be covered under insurance is the possible regulation of the industry in terms of qualification of personnel, standard treatment protocols, cost regulation etc., that might accompany it. Currently, healthcare services at home are provided without any regulation. Every organisation and individual are free to adopt the process that they want. Taking care of a patient at home is believed to be very different compared to a hospital and therefore the need to tailor existing treatment protocols according to the home environment. Some organisations have developed their own standard operating procedures (SOPs). For instance, an organisation that provides critical care has developed SOPs for delivering critical care outside the hospital to ensure that they follow disease/condition-based protocols conforming to international standards. A respondent explained that protocols specific to the type of care such as elder care, intensive care, palliative care, etc., need to be developed as each has distinct characteristics and requirements.

Among the organisations covered in the study, home healthcare companies are registered under the Companies Act, 2013, the non-profit organisation under the Societies Registration Act, 1860, the nursing bureau under the Delhi Shops and Establishments Act, 1954, while the home healthcare programme of the hospital is not registered as an independent entity. Such registration merely grants the organisations a legal status to operate in the country but does little to regulate the delivery of healthcare services. It is interesting to note that though the Central Act—the Clinical Establishments (Registration and Regulation) Act, 2010—does not regulate home healthcare as a service, the same is not necessarily true for state-specific clinical establishments legislation. For instance, a home healthcare company reported being registered under the Karnataka Private Medical Establishments Act, 2007 though its practical implications could not be ascertained in this study.

In India's National Policy on Senior Citizens, 2011, there is a brief mention of home care. The policy states that one of its focus areas is to "promote the concept of 'Ageing in Place' or ageing in one's own home, housing, income security and homecare services, old age pension and access to healthcare insurance schemes and other programmes and services to facilitate and sustain dignity in old age." (*National Policy for Senior Citizens, Government of India, 2011*). However, not much is known about the implementation and impact of the policy. Kerala is the first state to implement a palliative care policy and it has a home care component. The policy recommends home visits by trained personnel, that is doctors, nurses and allied health professionals for chronically sick or at-end-of-life-stage patients,

depending on their condition (*Kerala State Policy on Palliative Care, Government of Kerala, 2019*).

Stressing on the need for standardisation of processes and licensing of organisations, a respondent shared that many organisations provide untrained and unverified staff to work in people's homes. Since these organisations do not invest in their staff, they offer cheaper services. Though people may be inclined to use these cheaper services, they face problems such as the staff not providing proper care or quitting abruptly and the organisation not supplying a replacement. Since home healthcare is a fast growing sector in which the demand outstrips the supply, there is a need to bring order and structure into it. A respondent suggested that a home healthcare council should be formed to draft regulations for organisations engaged in home healthcare and regularise the training and qualification of service providers and the cost of services. In this context, the Maintenance and Welfare of Parents and Senior Citizens (Amendment) Bill, 2019, and voluntary accreditation which is a nascent phenomenon, may be helpful.

The Maintenance and Welfare of Parents and Senior Citizens (Amendment) Bill, 2019, may be the first step towards regulating home healthcare

The amendment proposed through the Maintenance and Welfare of Parents and Senior Citizens (Amendment) Bill, 2019, may be the first step towards regulating home healthcare, though it is essentially limited to care for the elderly. The Bill aims to improve the maintenance and welfare of senior citizens and provide standardisation of home care services. It proposes the registration of institutions providing home care services for senior citizens and prescribing minimum standards for them. In response to the questions raised by the Standing Committee on the Bill, the Ministry of Social Justice and Empowerment stated, "Home care services can have a very large scope – Home healthcare aides, diagnostics, doctor visits, physiotherapy services, food and nutrition and food supply, dialysis, terminal (end of life) care, counselling and emotional support to such senior citizens." The Ministry also stated that the home care services to senior citizens would be provided at a cost by trained and certified attendants through registered institutions. The cost of such care is stated to vary by various grades of home caregivers and across states. However, it has been three years since the Bill was introduced but it has not been passed yet.

The Ministry of Social Justice and Empowerment published model draft rules for home care and hospice care in June 2022. The rules have listed minimum standards for home care organisations to register. Once the Bill is passed, it will be up to the states to implement it and draft their own rules, which may be informed by the model rules.

In the absence of any standards and regulations, some organisations have opted for accreditation

Introducing voluntary quality checks in the home healthcare sector, some organisations have chosen to get themselves accredited. The Quality and Accreditation Institute (QAI), a private healthcare and laboratory accreditation body established in 2017, published standards for home healthcare in 2018 for the first time in India. These standards have been recognised by the International Society for Quality in Health Care (ISQua). As an accreditation body, the QAI assesses the offices of home healthcare companies, visits the patients' homes, reviews how providers are delivering different services, checks whether performance is according to the standards, safety protocols are in place, etc. For example, the companies that provide ICU setups at home need to have power backup facility. QAI gives accreditation to all the types of services being provided in home healthcare along with activities of daily living (QAI General Information brochure, January 2022) (Please see Annexure V for the home healthcare services accredited by the QAI). As per the information available on QAI's website, it has so far accredited five home healthcare organisations across India. The process and details of accreditation of home healthcare services were not within the scope of the study and were hence not pursued further.

CHALLENGES AND OPPORTUNITIES IN HOME HEALTHCARE

Apart from the financing and regulation related concerns discussed above, there are other challenges in delivering home healthcare services in India. These pertain to the availability and safety of providers, handling of emergencies and the management of biomedical waste. At the same time, the potential that it has shown in the last few years, especially during the COVID-19 pandemic, presents opportunities for growth.

CHALLENGES IN HOME HEALTHCARE

Unavailability of appropriate and adequate providers

The nature of the job requires the provider to be mature and have an empathetic and caring attitude, particularly those who have to be in the patient's home for long hours. However, providers with such attitude and aptitude are scarce. Instances of providers quitting without notice or even without informing are not uncommon in home healthcare. A couple of incidents of theft at patients' homes were also reported. Vocational training often does not prepare providers adequately for the role. Different organisations are usually involved in training, placement and hiring, because of which, a communication gap sets in, leading to a mismatch between the candidates' expectations and what the job entails. Thus, though candidates enrol for the training enthusiastically, many drop out as they are reluctant to perform tasks like changing the patients' clothes and diapers. To overcome this, some training institutions counsel the prospective candidates before enrolling them. They give them a clear understanding of the home health sector, what work they would be required to do, how much they could expect to earn, career advancement, etc. The representative of one such training institution shared that only seven to ten candidates may join the training out of the 100 that they counsel but their probability of continuing in the sector is higher.

Recruiting and retaining nurses to provide healthcare services at home is also a challenge. Nurses, particularly female nurses, prefer to work in hospitals rather than homes for reasons of safety and convenience, though they may be paid twice as much in home healthcare. As the head of a hospital's home care programme revealed, "There is no feeling of security in a patient's home. Nurses also have concerns like, will my husband let me go to someone's house? ...even with twice salary, they are not willing to work in homes because of distance from home to patient's home, different place to go for every patient unlike hospital duty, home care may also involve more night shifts." Nurses with B.Sc. nursing degrees do not prefer to work in homes because of the long working hours and families not treating

them with respect. "B.Sc. nurses don't like doing private nursing because the workload is more you see, they are working for 12 hours and the patient's relatives don't look after them," said the head of a nursing bureau.

Travel and logistics challenges

The convenience that home healthcare offers the patients is offset by the travel that the providers need to undertake. In contrast to working in a hospital which has a fixed location, the location and travel logistics change with every patient in delivering healthcare services at home. For this reason, some providers who work independently render services only in areas near their house. The non-profit organisation provides a vehicle to the home care team to commute from the organisation's office to the patients' homes. Some home healthcare companies try to allocate cases to providers who reside closer to the patient's home. One respondent reported having to handle trivial issues like finding a parking spot for the doctor's vehicle and the need to make the doctor's home visit process smooth, otherwise they would be reluctant to make a visit the next time.

The providers get exhausted while providing services for a long duration, particularly the 24x7 kind of service, if they do not receive adequate rest and sleep. A respondent observed that it may become difficult for the provider to stay at home with the patient all day for weeks or months together, "Woh diwar uske liye jail ki terah ho jaati hai (walls of the house become like a prison for the provider)." This becomes especially challenging when offering assisted living to an elderly person as the provider must be available round-the-clock. Some families are unwilling to give them time off even for a short period without a replacement.

Lack of safety, dignity and respect of providers

Incidents of physical and sexual abuse of the providers at patients' homes are fairly common, mostly perpetrated by older men or patients with mental health conditions or dementia. Some respondents mentioned that the act may not be intentional as patients with mental health conditions might not be conscious of their own behaviour. Verbal abuse by elder patients was also reported. Sharing his experience, a male nursing aide said, "But with their emotional level, what can they do when they are over 75 years? The one who has lived his life all by himself without a wife. What can he do? He can only masturbate. I have seen when he is masturbating. After seeing that, how we can go back and touch him? I told them that even though he was 75 years he has those sexual feelings. So, I cannot handle him."

"One incident happened, madam, there was an aged uncle who went to the staff room at night and misbehaved with one of the staff (female), so we closed the package," shared the nursing head at a home healthcare company.

Another nursing aide said, "He was mentally retarded. When we're fast asleep, suddenly he'd get down. He'd move little by little, get down and hold my feet. He'd ask, "Who are you,

man... sleeping at my home? Are you a thief?" He would shout, I'll get shocked to hear this at 12 or 1 o' clock."

In some instances, the organisations discontinue services in such homes, while in others, they resolve it by talking to the families, arranging frequent home visits by the supervisor, or by sending a substitute provider. The family members may not be aware of such incidents or may ignore them. Like a nursing aide shared, "That lady, unwilling to accept her father's mistake, said if you don't want to work, you can leave. But for that you cannot blame my father, 75 years old person, who is also like a father to you."

"Like you know old people, they have female nurses, they try to bully them, do all the things which they should not. If they tell us, we take it up...one patient tried to do it ki nurse mereko massage karo (give me massage) then she called his daughter, she called his wife and jhaada unko (screamed at him)," said the head of a nursing bureau.

Providers also face safety issues due to the presence of pets at patients' homes. Some companies check for pets in the household at the time of home assessment. A respondent shared an instance when the provider was not able to go inside the patient's home because there was no one to tie the dog who is known to be aggressive towards visitors.

Sometimes, the families "ill-treat" or "harass" the providers and get very demanding. When the patient is sleeping, they say, "ye toh khali baitha hai (he is sitting idle)," and expect the providers to assist in household chores, kitchen work or visit the market. Other concerns are related to the families' discriminatory behaviour such as asking providers to use toilets outside the home, restricting the use of certain utensils, not offering freshly cooked food or adequate meals in case of 12 or 24 hour shifts, not respecting food habits such as rice for people from the north-east or southern states, giving tap water to drink, or not providing bedding to rest through the night shift. "We close the service if proper facilities are not provided. There are people who make a caregiver sit on a plastic chair right through the night, that's not okay. It is our job to make sure that the care giver is attended," said the CEO of a home healthcare company.

Sometimes families interfere unduly with the provider's work. For instance, the entire family surrounds the doctor, and the doctor finds it difficult to interact only with the patient. It becomes a time-consuming process for the doctor. Similarly, they also keeping interfering with nurse's activities. "... You know they stand on the nurse's head. They don't want to work at home. They say, bohut tang karte hain...aapne aisa diaper change kyun kiya, aapne ye kyun nahi kiya, aapne vo (families trouble a lot, why did you change the diaper this way, why did you not do this). If she's a trained nurse, she knows her job well, let her do it. And then you intervene. Don't intervene before that," the head of a nursing bureau said.

While commenting on the lack of respect for nurses, a respondent, the head of a hospital's home care programme, pointed out, "Everywhere they call us 'sister'. We are professionals, don't call us sister, all this emotional stuff, we demand to be treated with respect and dignity

in the workplace." Another respondent, a nursing aide, felt that they should be treated with respect and given incentives to stay in the workforce, "There is free ticket for police to travel. We save a life. There is no free thing for us. Doctors, you all know, their salary will be of big scale, depending upon the case or surgery. For our nursing there is nothing."

Limited resources at home could limit interventions

Handling emergencies at home: Handling emergencies at home is a challenge as there are limited resources and only certain interventions can be provided. "In hospital, if a patient has any emergency, it can be managed, there's everything in the hospital, at home we can only do limited. If the patient starts bleeding, we can stop it for some time by giving an injection or something but not after that. If it is more, then it can be managed in the hospital only," said a nurse at the non-profit organisation. The provider's ability to manage an emergency at home is another aspect. For instance, if the patient collapses and the nurse panics, then the situation could get worse as there would be no one else to take care of the patient. Hence the providers must be well trained and prepared for any eventuality.

Conducting radiological investigations at home: Currently, X-rays, ECGs and Holter monitoring are some of the radiological investigations that are feasible at home. A respondent shared that when they started offering ECG services at home, they realised that there should not be any metals around the patient, on the bed, walls, etc. Even with X-rays, though the radiation in digital X-rays is not very strong, the technician has to take precautions such as standing behind a wall, ensuring that only the patient is in the room and ensuring the clarity of the X-ray film. Investigations such as MRI, CT scan and stress Echo cannot be performed at home because of the structure of the machines and ultrasonography cannot be conducted because of regulatory restrictions.

Challenge of managing biomedical waste

Management of biomedical waste (BMW) is a concern in home healthcare. One organisation's staff carries the waste that is generated in providing services at home, back to the organisation's collection centre, from where it is disposed of as per guidelines. However, most of the organisations and individual providers do not do so. In most cases, the biomedical waste generated at home is disposed of along with the regular household waste. Since home healthcare is not recognised as 'healthcare', the Pollution Control Board does not give a license for BMW management. However, this varies across states. An organisation in Haryana got a license for BMW management. Collection of BMW waste from homes is a challenge as the collection agency will not visit hundreds of individual homes.

OPPORTUNITIES FOR HOME HEALTHCARE

Demand and availability of home healthcare services has increased manifold in the last decade

The manager of a home healthcare company observed, "When it was starting in 2008–2010, ****(company) came, since then the industry saw a boom. There are more than 10 plus organisations in Delhi NCR only that are providing services. These are the big organisations and small ones there may be 1,000 in Delhi NCR, they are what we call bureaus." One reason for healthcare at home being in demand is the convenience it offers to the families. It saves their time and effort in taking the patient to the hospital. Having a nurse to care for the patient at home relieves the family's physical and mental stress. The changing family structure is another reason for the growing need, as observed by the head of a nursing bureau, "I see that more people will be required because now there are fewer people at home to take care. Suppose somebody is sick, and there is no one to take care of them. So, you'll be needing these services more and more, especially in nuclear families."

The demand for specialised medical care at home, such as ICU type of services is on the rise too. Patients may be admitted to the ICU in the hospital for long periods or multiple times before they fully recover. This raises the risk of opportunistic infection and places a financial and emotional burden on the families. Critical care at home proves beneficial in such situations and is also more economical than hospitals.

One area in which healthcare services at home are immensely beneficial for patients and their families is palliative care. Palliative care at home for people with cancer and others who are at the end-of-life stage helps in symptomatic management and reducing the need to take the patient to the hospital repeatedly. A patient suffering from cancer revealed, "I had pain in the stomach and feet, infection in the soles, so had gone to ***(hospital) to show the doctor. A bhaiya sitting there said I'll give you a number, you are in so much trouble, you need not come here, there's so much rush here. NGO waali ayengi, wahin tumhe dawai de dengi toh tumhe itni pareshani nahi hogi (a person from the NGO will come home and give medicine, you will have not have to face so much trouble)." Palliative care at home reduces the family's stress and allows the patient to remain close to their families, including at the time of death. Otherwise, if the patients are admitted to the ICU in the hospital, they are not able to see their family members.

Because of the rising demand, there are plenty of job opportunities in this sector. "Employment opportunities were available for all home health trained students. Many of them received calls from home health companies like *** homecare, ***, some candidates were absorbed by *** and worked under the supervision of nurses," said the in-charge of a vocational training course.

During the COVID-19 pandemic, home healthcare expanded as an alternative to hospital care

The COVID-19 pandemic pushed the case of home healthcare further. Many individuals with minor symptoms of COVID-19 chose home healthcare isolation packages that comprised regular health monitoring, virtual consultations, testing, drug delivery at home and need-based referrals to hospitals. The various home-based care strategies adopted by the states to contain the spread of COVID-19 have been emphasised in NITI Aayog's study on 'Home-based management of COVID-19' published in December 2021. The report concludes that home-based care, a low-cost healthcare model with the ability to reach many patients, particularly with the use of digital tools, emerged as an important pillar of pandemic management. The COVID-19 pandemic helped in influencing people's decisions regarding home management of diseases. While emerging as an alternative to hospital care. its potential to complement hospital demonstrated. According to a respondent, a lot of health care including many procedures have been delivered at home during and since the pandemic.

The palliative care at home provided by the non-profit organisation proved particularly beneficial to cancer patients during the lockdown phase. "There were no hospitals at that time. We were going daily during lockdown, took all precautions, as per protocol, wore kits and went, if cancer patient got corona, we provided such care too during COVID," revealed a nurse at the non-profit organisation.

Learning from the COVID-19 experience, a couple of respondents recommended exploring community home healthcare type of models. They suggested that the Residents Welfare Associations could develop a separate fund and use it to arrange for doctor's home visit in case of emergencies or employ one or two nurses in the community hall along with some beds.

CONCLUSION

The study offers insights into the various facets of home healthcare, such as services offered, users, providers, organisations engaged in providing home healthcare, service delivery mechanisms, and challenges and opportunities for the sector.

Assistance with activities of daily living along with routine nursing procedures is the most sought after service, primarily because the largest user group is the elderly population. Consequently, a greater proportion of services at home is provided by the untrained aide and trained caregivers who have undergone vocational training. The multiple categories of trained caregivers, though have different nomenclature, perform similar roles. The involvement of three ministries of the Government of India; the Ministry of Health and Family Welfare (MoHFW), the Ministry of Skill Development and Entrepreneurship (MSDE) and the Ministry of Social Justice and Empowerment (MSJE) in developing the course curricula and delivering vocational training leads to duplication and overlap. For instance, two new trainee courses approved by the MSDE in March 2022 (General Duty Assistant Trainee – 2022 and Home Health Aide Trainee – 2022) are open for candidates aged 14 years and above. Whether such young candidates would have the maturity, attitude and aptitude to tend to patients in homes needs to be considered while designing such courses. Streamlining the qualification, training, nomenclature, skills, roles and career progression of trained caregivers will help in standardising their services.

The other commonly used healthcare service at home comprises specialised services for patients who have been discharged from hospital and need follow-up care. However, there are no guidelines or standard operating procedures on how such care should be provided at home. Some organisations have formulated their own procedures. This study highlights the need for developing standardised processes to deliver care for different conditions at home, including aspects such as biomedical waste management.

The informal nature of the home healthcare sector is changing as some private home healthcare companies and hospitals put in place standard procedures for themselves. (NATHEALTH, 2022). However, these companies offer services mainly through providers who are not on their rolls but deployed as independent consultants, and for whom the company takes little responsibility. Usually, the contract signed between the company and the user absolves the company of any responsibility for the provider's conduct. At the same time, since such providers are not employed with the company, they are not entitled to organisational benefits such as fixed monthly salary, health insurance, paid leave, provident fund, etc. Thus, though the private home healthcare companies may be

steering the sector towards structured and formal processes, they too currently function in an informal manner in certain respects.

In the absence of standards and regulations to govern home healthcare services in India, there are concerns about the quality of services (IANS, 2017). Further, there are no grievance redressal mechanisms for users and providers. While the Maintenance and Welfare of Parents and Senior Citizens (Amendment) Bill, 2019, when enacted, could initiate the process of regulation of home healthcare services for the elderly, a wider perspective and consultation is required to address the functioning of the sector. Similarly, the demand to cover home healthcare under insurance, calls for a larger discussion about whether and how that could be feasible. The limited reach of home healthcare services due to cost constraints is a concern that would have to be addressed to meet the rising need for these services. At present, there are almost no government programmes or schemes that offer subsidised care or financial assistance to avail healthcare at home.

There are certain limitations of the study. Being exploratory in nature, the study provides an overview of the home healthcare sector without delving deep into its various dimensions. Future studies may explore the user and provider perspective in greater detail, such as the socioeconomic aspects, provider profile and motivation to work in the home healthcare sector, supervision and training provided by home healthcare organisations, as also the accreditation and quality aspects. The delivery mechanism varies across different types of home healthcare organisations and is also influenced by the scale of their operations. Research on specific types of organisations would therefore highlight the diversity and unevenness that exists, which is important to inform policy intervention on the issue. Though primary data collection was mainly within the Delhi NCR region, many respondents offer services in other parts of the country as well. To that extent, the findings present a wider picture and are not restricted to the Delhi NCR region. However, studies covering other geographies and state-specific processes and initiatives would provide valuable information and throw light on other attributes.

Considering its demographic, epidemiological and sociocultural context, the international experience beckons India to reflect upon how home healthcare can be integrated into the country's health system. As has happened in several other countries, India too must develop its own meaning and model of home healthcare according to its requirement and resources.

REFERENCES

- Agarwal, K. (2020, August 13). India's Population Will Be 1.52 Billion by 2036, With 70% of Increase in Urban Areas. *The Wire*. https://thewire.in/government/india-population-growth-government-report-2036-projections-urban-migration
- Anderson, C. (2010). Presenting and Evaluating Qualitative Research. *American Journal of Pharmaceutical Education*, 74(8).
- Arokiasamy, P. (2018). India's escalating burden of non-communicable diseases. *The Lancet Global Health*, 6(12).
- Bains, P., & Minhas, A. S. (2011). Profile of Home-based Caregivers of Bedridden Patients in North India. *Indian Journal of Community Medicine*, *36*(2), 114–119.
- Balasubramanian, N., Shetty, A. P., & Rao, T. S. S. (2017). An Evaluative Study of Video Assisted Teaching Module (VATM) on Homecare of Schizophrenic Patients developed for Primary Caregivers at Mangaluru. *Asian Journal of Nursing Education and Research*, 7(1), 53.
- Creswell, J.W. (2013). *Qualitative inquiry and research design: choosing among five approaches.* SAGE Publications.
- Denzin, N. K., & Lincoln, Y. S. (Eds). (2011). Introduction: The Discipline and Practice of Qualitative Research. In *The SAGE Handbook of Qualitative Research*. Sage Publications. https://doi.org/10.1177/1035719x1101100208
- Dias, A., Dewey, M. E., D'Souza, J., Dhume, R., Motghare, et al. (2008). The Effectiveness of a Home Care Program for Supporting Caregivers of Persons with Dementia in Developing Countries: A Randomised Controlled Trial from Goa, India. *PLoS ONE*, *3*(6), e2333. https://doi.org/10.1371/journal.pone.0002333
- Ga H. (2020). Long-Term Care System in Korea. *Annals of Geriatric Medicine and Research*, *24*(3), 181–186. https://doi.org/https://doi.org/10.4235/agmr.20.0036
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(117).
- Genet, N., Boerma, W., Kroneman, M., Hutchinson, A., & Saltman, R. B. (Eds). (2012). Home Care across Europe Current structure and future challenges. World Health Organization.
- Goldsmith, L. J. (2021). Using framework analysis in applied qualitative research. *The Qualitative Report*, *26*(6), 2061–2076.
- Gopal, M. S. (2022). Telangana districts get free palliative care facilities. *Telangana Today*. https://telanganatoday.com/telangana-districts-get-free-palliative-care-facilities
- Halemani, K., Shashidhara, Y. N., & D'Souza, S. R. B. (2021). An Evaluative Study to Assess the Effectiveness of a Video-Assisted Teaching Module on Knowledge and Practice Regarding

- Home-Based Colostomy Care of Children Among Primary Caregivers in Selected Hospital Lucknow, Uttar Pradesh. *Indian Journal of Surgical Oncology*, *12*(1), 146–151.
- Hunter, D. J., McCallum, J., & Howes, D. (2018). Defining Exploratory-Descriptive Qualitative (EDQ) research and considering its application to healthcare. In *Proceedings of Worldwide Nursing Conference 2018*.
- Hunter, D. J., McCallum, J., & Howes, D. (2019). Defining Exploratory-Descriptive Qualitative (EDQ) research and considering its application to healthcare. *Journal of Nursing and Health Care (JNHC)*, 4(1).
- IANS. (2017, April 3). Home healthcare gaining ground, but what about regulations? *Financial Express*. https://www.financialexpress.com/lifestyle/health/home-healthcare-gaining-ground-but-what-about-regulations/612894/
- Indian Council of Medical Research, Public Health Foundation of India, & Institute for Health Metrics and Evaluation. (2017). *India: Health of the Nation's States The India State-Level Disease Burden Initiative.* New Delhi, India: ICMR, PHFI, and IHME.
- International Institute for Population Sciences. (2020). National Family Health Survey-5, 2019–2021 India Fact Sheet. Ministry of Health and Family Welfare.
- Janardhana, N., Raghunandan, S., Naidu, D. M., Saraswathi, L., & Seshan, V. (2015). Care giving of people with severe mental illness: An Indian experience. *Indian Journal of Psychological Medicine*, *37*(2), 184–194. https://doi.org/10.4103/0253-7176.155619
- Jayalakshmi, R., & Suhita, C. C. (2017). Home-based Palliative Services under Two Local Self-government Institutions of Kerala, India: An Assessment of Compliance with Policy and Guidelines to Local Self-government Institutions. *Indian Journal of Palliative Care*, Jan–Mar *23*(1), 65–70. https://doi.org/10.4103/0973-1075.197947
- Jha, A. (2019). Home-based dialysis: An emerging industry. *Economic Times Health World*. https://health.economictimes.indiatimes.com/news/industry/home-based-dialysis-an-emerging-industry/72899293
- Kalkonde, Y., Deshmukh, M., Nila, S., Jadhao, S., & Bang, A. (2019). Effect of a community-based intervention for cardiovascular risk factor control on stroke mortality in rural Gadchiroli, India: study protocol for a cluster randomised controlled trial. *Trials*, *20*(1), 764. https://doi.org/10.1186/s13063-019-3870-x
- Kandhari, R. (2018). Max Healthcare's contrarian bet. *The Ken*. https://the-ken.com/story/max-healthcares-contrarian-bet/?searchTerm=Home healthcare
- Kerala State Policy on Palliative Care, Government of Kerala, 2019.
- Khosla, D., Patel, F. D., & Sharma, S. C. (2012). Palliative care in India: Current progress and future needs. *Indian Journal of Palliative Care*, *18*(3), 149–154. https://doi.org/10.4103/0973-1075.105683
- Kiersey, R. A., & Coleman, A. (2017). Approaches to the regulation and financing of home care services in four European countries. An evidence review. *Health Research Board, Dublin.*
- Kothari, C. R. (2004). *Research Methodology: Methods and Techniques* (Second Rev, Issue December). New Age International (P) Limited, Publishers.

- Kulothungan, V., Sathishkumar, K., Leburu, S., ... & Mathur P. (2022). Burden of cancers in Indiaestimates of cancer crude incidence, YLLs, YLDs and DALYs for 2021 and 2025 based on National Cancer Registry Program. *BMC Cancer*, 22, 527 (2022). https://doi.org/10.1186/s12885-022-09578-1
- Kumar, S. (2013). Models of delivering palliative and end-of-life care in India. *Current Opinion in Supportive and Palliative Care*, 7(2), 216–222. https://doi.org/10.1097/SPC.0b013e3283610255
- Landers, S., Madigan, E., Leff, B., ... & Breese, E. (2016). The Future of Home Health Care: A Strategic Framework for Optimizing Value. *Home Health Care Management & Practice*, 28(4), 262–278. https://doi.org/10.1177/1084822316666368
- Lindley, R. I., Anderson, C. S., Billot, L., ... & Sebastian, I. (2017). Family-led rehabilitation after stroke in India (ATTEND): a randomised controlled trial. *The Lancet*, *390*(10094), 588–599. https://doi.org/10.1016/S0140-6736(17)31447-2
- Magazine, A. (2022, July 13). India's demography at crossroads: Elderly may outnumber the youth. *The Indian Express*. https://indianexpress.com/article/business/economy/indiademography-at-crossroads-elderly-may-outnumber-the-youth-8025664/
- Malik, C., Khanna, S., Jain, Y., & Jain, R. (2021). Geriatric population in India: Demography, vulnerabilities, and healthcare challenges. *Journal of Family Medicine and Primary Care*, 10(1), 72–76. https://doi.org/10.4103/jfmpc.jfmpc
- Menon, G. R., Yadav, J., & John, D. (2022). Burden of non-communicable diseases and its associated economic costs in India. *Social Sciences & Humanities Open*, *5*(1).
- Ministry of Statistics and Programme Implementation. (2021). *Persons with Disabilities* (Divyangjan) in India A Statistical Profile : 2021.
- Ministry of Statistics and Programme Implementation. (2022). Youth in India 2022.
- MoHFW. (2020). Longitudinal Ageing Study in India (LASI) Wave 1, 2017–18, India Report. Government of India.
- Murashima, S., Nagata, S., Magilvy, J. K., Fukui, S., & Kayama, M. (2002). Home Care Nursing in Japan: A Challenge for Providing Good Care at Home. *Public Health Nursing.19*(2),94–103. https://www.researchgate.net/publication/11500606_Home_Care_Nursing_in_Japan_A_Challenge_for_Providing_Good_Care_at_Home
- Nandi, J. (2020). Private hospitals offer remote monitoring, care at home for Covid-19 patients. *Hindustan Times*. https://www.hindustantimes.com/india-news/private-hospitals-offer-remote-monitoring-care-at-home/story-qhMF60aUn9wnQDSKJjklZI.html
- NATHEALTH. (2022). *Indian Home Healthcare 2.0: Redefining the Modern Care Continuum* (Issue March).
- National Commission on Population. (2020). Census of India 2011 Population Projections for India and States 2011–2036. Ministry of Health and Family Welfare, Government of India. https://main.mohfw.gov.in/sites/default/files/Population Projection Report 2011-2036 upload_compressed_0.pdf
- National Health Mission. (2019). *We Care: Good, Replicable and Innovative Practices.* Ministry of Health and Family Welfare (MoHFW), Government of India.

- National Policy for Senior Citizens, Government of India, 2011.
- National Sample Survey Organisation. (2001). Concepts and Definitions Used in NSS. Ministry of Statistics & Programme Implementation, Government of India
- NITI Aayog. (2021a). *Home-based Management of COVID-19: Best Practices Adopted By States*. https://www.niti.gov.in/sites/default/files/2021-11/State-practices-on-home-based-care-forCOVID-19.pdf
- NITI Aayog. (2021b). Investment Opportunities in India's Healthcare Sector.
- Pacific Bridge Medical. (2014). *The Expanding Home Healthcare Market in Asia.* https://www.pacificbridgemedical.com/publication/the-expanding-home-healthcaremarket-in-asia/
- Pagaiya, N., Noree, T., Hongthong, P., ... & Setheetham, D. (2021). From village health volunteers to paid care givers: the optimal mix for a multidisciplinary home health care workforce in rural Thailand. *Human Resources for Health*, 19(1), 1–10.
- Pandey, V. (2021). Covid-19 in India: Patients struggle at home as hospitals choke. *BBC News*. https://www.bbc.com/news/world-asia-india-56882167
- Philip, R. R., Venables, E., Manima, A., Tripathy, J. P., & Philip, S. (2019). "Small small interventions, big big roles"- a qualitative study of patient, care-giver and health-care worker experiences of a palliative care programme in Kerala, India. *BMC Palliative Care*, 18(1), 16. https://doi.org/10.1186/s12904-019-0400-2
- Pimdee, A., & Nualnetr, N. (2017). Applying the International Classification of Functioning, Disability and Health to guide home health care services planning and delivery in Thailand. *Home Health Care Services Quarterly*, 36(2), 81–95.
- Porecha, M. (2020). Covid homecare can't cover the home stretch in India. *The Ken.* https://the-ken.com/story/covid-home-care-cant-cover-the-home-stretch-in-india/?searchTerm=Home healthcare
- Sagar, R., Dandona, R., Gururaj, G., ... & Dandona, L. (2020). The burden of mental disorders across the states of India: the Global Burden of Disease Study 1990–2017. *The Lancet Psychiatry*, 7(2), 148–161. https://doi.org/10.1016/S2215-0366(19)30475-4
- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing and Health*, *23*(4). https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g
- Shajahan, A. (2022). *Blog:* What is the point of being a doctor if I can't treat my own mother. *NDTV*. https://www.ndtv.com/blog/what-is-the-point-of-being-a-doctor-if-i-cant-treat-my-own-mother-3342888
- Singh, A., & Chaudhari, V. (2020). Drivers of home health nursing profession. *Indian Journal of Forensic Medicine and Toxicology*, *14*(4), 7157–7162. https://doi.org/10.37506/ijfmt.v14i4.12775
- Singh, A., Jha, A., & Purbey, S. (2020). Perceived Risk and Hazards Associated With Home Health Care Among Home Health Nurses of India. *Home Health Care Management and Practice*, 32(3), 134–140.

- Singh, P., Thukral, G., Joseph, PC, & Sahoo, B. (2019). Unplanned Readmission to Hospitals at Home Care Set up in India A Comparative Study. *American Journal of Nursing Science*, 8(6).
- Sinha, S., Prasad, I., & Prasad, P. (2020). Dementia and the Challenges of Caregiving: A Personal Account. *Economic & Political Weekly*, *55*(14).
- Stebbins, R. A. (2001). *Exploratory research in the social sciences*. (Vol. 48). Sage Publications.
- Tarricone, R. & Tsouros, A. D. (2008). Home care in Europe: the solid facts. *World Health Organization*. https://apps.who.int/iris/handle/10665/328766
- Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: Systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, *18*(1), 1–18. https://doi.org/10.1186/s12874-018-0594-7
- Vimala, G. (2013). Effect of Video-Assisted Teaching Module on Home Care Management of Children with Mental Retardation. *Nursing Journal of India*, *104*(2), 79–80.
- Welch, H. G., Wennberg, D. E., & Welch, W. P. (1996). The Use of Medicare Home Health Care Services. *The New England Journal of Medicine*, *335*(5), 324–329.
- Western Cape Government. (2011). National guidelines on home-based care / community-based care. https://www.westerncape.gov.za/general-publication/national-guidelines-home-based-care-hc-and-community-based-care-cc
- WHO Initiative on Home-Based Long-Term Care. (2002). Community home-based care in resource-limited settings: a framework for action. *World Health Organization*. https://apps.who.int/iris/handle/10665/42523
- Won, C. W. (2013). Elderly long-term care in Korea. *Journal of Clinical Gerontology and Geriatrics*, 4(1), 4–6. https://doi.org/https://doi.org/10.1016/j.jcgg.2012.11.001
- Wu, Y. P., Thompson, D., Aroian, K. J., McQuaid, E. L., & Deatrick, J. A. (2016). Commentary: Writing and evaluating qualitative research reports. *Journal of Pediatric Psychology*, 41(5), 493–505. https://doi.org/10.1093/jpepsy/jsw032
- Yeager, A., LaVigne, A. W., Rajvanshi, A., Mahato, B., Mohan, R., Sharma, R., & Grover, S. (2016). Cansupport: A model for home-based palliative care delivery in India. *Annals of Palliative Medicine*, *5*(3), 166–171. https://doi.org/10.21037/apm.2016.05.04

ANNEXURES

Annexure I: Characteristics of Respondents

	1	teristics of Resp		Dame 3 -		
Respondent identification number	Sex	Description	Online/ In-person interview	Remarks		
Patients or their family members						
R10	F	R10, wife of a cancer patient	In-person	Her husband (aged 47 years) was diagnosed with cancer in May/June 2021 and is now bedridden, could not sit up or stand by himself.		
R11	F	R11, cancer patient	In-person	She was diagnosed with cancer in 2019 and is now bedridden, could not sit up or stand by herself.		
R12	F	R12, daughter of a geriatric patient	In-person	Her mother (aged 94 years) was diagnosed with age-related atrophy of the brain in 2021.		
R13	F	R13, wife of a cancer patient	In-person	Her husband (aged 54 years) was diagnosed with lung cancer 20 years back and was diagnosed with brain metastases in 2021.		
	•		Provid			
R1	F	R1, a nurse who provides services at home independently and is employed full-time in a hospital	In-person	Trained nurse (GNM), working in a hospital since 2007. She has been doing home visits for last eight years.		
R6	F	R6, counsellor at a non-profit organisation	In-person	Trained in social work (MSW), working with a non-profit organisation for the last five years.		
R7	F	R7, nurse at a non-profit organisation	In-person	Trained nurse (ANM), who was working in hospitals for about 17 years and has been doing home visits for last five years.		
R8	F, 30	R8, doctor at a non-profit organisation	In-person	Trained doctor with a certification in palliative medicine and has been working in palliative care for more than three years.		
R9	F	R9, nurse at a non-profit organisation	In-person	Trained nurse, working with a non-profit organisation for last seven years.		
R19	M	R19, nursing- aide who works independently as well as through organisations	Telephonic	Certified as a diploma in general nursing (2 years course), working in hospitals and patient homes for last six years.		
R20	M	R20, independent physiotherapist	Telephonic	Trained physiotherapist (MPT), practising physiotherapy for last 17-18 years and also conducts home visit.		
R22	F	R22, nursing head at a home healthcare company	Telephonic	Trained nurse (Post BSc Nursing) has 25 years of experience in nursing and working in home healthcare for last seven years.		

		Organisation	is engaged in h	nome healthcare
R2	М	R2, CEO of a home healthcare company	In-person	Founder and Chairperson of a home healthcare company founded in 2016 with a focus on providing intensive care at home.
R4	M	R4, manager of a home healthcare company	Telephonic	Trained in healthcare management and has been working for healthcare startups for last ten years including home healthcare.
R17	F	R17, Head of a hospital's home healthcare programme	In-person	Trained nurse (MSc Nursing), heading the home healthcare department of the hospital since its inception in 2017 and has been working as a nurse for more than 20 years.
R21	F	R21, co-founder of a home healthcare company	Written responses	Managing Director, Co-Founder and Chairperson of a home healthcare company founded in 2013.
R23	M	R23, manager at a non-profit organisation	In-person	Working with a non-profit organisation.
R24	F	R24, head of a nursing bureau	In-person	Trained nurse, who started her own nursing bureau in 1984 and has been providing services/ providers since then.
R14	F	Helpline counsellor at a non-profit organisation	In-person	Working with a non-profit organisation
R15	F	Coordinator at a non-profit organisation	In-person	Working with a non-profit organisation
R16	F	Quality assurance executive at a non-profit organisation	In-person	Working with a non-profit organisation for the last three years.
	<u>l</u>		raining Institu	tions
R3	М	R3, CEO of a non-statutory standard setting body for vocational training	In-person	Chief Executive Officer of the non-statutory standard setting body in the field of healthcare vocational education and skill development for last eight years.
R5	F	R5, in-charge of a vocational training course	In-person	Administrative in-charge of home health aide training course and ran three batches but was discontinued in 2020 because of COVID-19.
R18	М	R18, manager of a training institution cum home healthcare company	Telephonic	Trained in business administration (MBA), working with skill development and education companies for more than six years.
			ne expert cons	ultation
R25	M	R25, CEO of an accreditation body that accredits home	Video	Founder – Chief Executive Officer of healthcare and laboratory accreditation institution founded in 2017.

		healthcare companies		
R26	М	R26, CEO of a home healthcare company	Video	Founder – Chief Executive Officer of a home healthcare company founded in 2012.
R27	F	R27, medical director at a non-profit organisation	Video	Trained doctor with specialisation in palliative medicine, working with non-profit organisation for last 13 years.

F=female

M=male

ANM= Auxiliary Nurse Midwifery; GNM=General Nursing and Midwifery; MBA = Master of Business Administration; MPT = Master of Physiotherapy; MSW= Master of Social Work;

Annexure II: Interview Guides

Interview guide of Patients or Home Healthcare Users

<u>Patients or home healthcare users</u> are current users of home healthcare services or those who used such services in the last one year, belonging to any age group (prior to the date of interview). These may be people affected by chronic health conditions such as cardiovascular diseases, respiratory diseases, diabetes, cancer, HIV/AIDS, renal conditions, musculoskeletal diseases, mental health conditions; or age-related health conditions; or persons with disabilities; or people recovering from illnesses/ surgeries, post-hospitalisation.

Thank you for taking the time to meet with me today. I would like to talk to you about your experience of availing home healthcare services. (If the Patient/home healthcare user is not available, please interview the adult household member)

Background Information

Name	Age	Sex	Education	Occupation
Family members:				
Age	Sex		Relation to respondent	

Currently Employed: Yes / No

If yes, nature of employment

Couple of lines about the patient's socio economic condition as per the interviewer's observation of home, family etc. (subjective description)

Theme 1: Scope of home healthcare services

- 1. Can you please tell us about the disease/condition for which you are using home healthcare services? Probe:
 - For how long have you had the disease/ condition?
 - Who is the primary caregiver in your house-their age, sex, relationship with respondent?
 - Who introduced/referred you to home based care services?
- 2. Can you please tell us about the health care services you are currently using at home?
 - What are the services you are currently using?
 - For how long have you been using the services of the current provider(s)/institution?
 - Have you used the services of other care providers for home health care? Ask for details-who, when, what services, for how long, why discontinued?
 - Do you know anyone else who is using home healthcare services? If yes, could you please tell us something about their services-what services, who is the provider etc.?
- 2. Are there any other health services you require at home but are not able to get? If yes, why?
 - Do you have any suggestions for adding more services in home healthcare?

Theme 2: Profile of home healthcare providers

- 4. Can you please tell us about your experience with home healthcare providers?
 - Please name the type of providers such as doctors, nurses, etc. that are providing services.
 - What is their qualification, age, sex, how long he/she has been providing you home health services?
 - Do you know anything about their training and experience in home healthcare?

Theme 3: Interaction between patients, providers, and organisations engaged in home healthcare

- 5. Can you please describe your engagement with the provider and institution?
 - How did you come in contact with your provider and institution?
 - How is the provider's timing, duration and frequency of service decided?

- Is there any formal service contract between you and your provider/institution? If yes, please elaborate- who prepared the contract, what all does it cover.
- Can you tell us about the job description of your provider, remuneration, leave entitlement and other benefits?
- 6. While providing home health care services:
 - What measures do providers take to ensure your safety and of themselves at the home?
 - Is there any mechanism or someone who monitors their work? Please elaborate.
 - Have you ever had complaints about your provider? Is there any mechanism to register your complaints? Please give examples.
 - Have providers ever had any concerns about the working conditions at home? Please give examples.
 - What are the arrangements for food, water, toilet, rest/sleep for the provider while they are at your home?
- 7. Is there a mechanism to ensure continuity of care between home and hospital? *If ever referred:*
 - Where do providers refer you in case of emergency?
 - In what conditions have you been referred to? Please give examples.
 - Is any support provided in case of referral, such as arranging for transportation, informing the referral hospital etc.?
- 8. What is the mode of payment to the provider?
 - Do you pay directly to the provider (or to the institution) and how often? How is the cost decided?
 - Is there any defined home healthcare service package that you are using? If yes, could you please elaborate what does it cover, e.g., consultation charges for each visit by a doctor, physiotherapist, cost of services, drugs, and consumables, etc? or cost of single service or packages that include certain services for defined hours, days, etc
 - Have you ever used or are currently using any insurance package? If yes, ask for details of the insurance benefit, who/what is covered or excluded, payment mechanism.
 - Are there any challenges in using insurance to cover home healthcare? Please elaborate. Ask for examples of when it worked well and when it did not work well.
- 9. Are you aware of any government programs related to home healthcare services? For example, for senior citizens, palliative care etc.?
 - If they mention any, request to describe how they affect them or home healthcare in general?
 - 10. What do you think about the scalability and usefulness of home healthcare services in India?
 - What are the benefits and strengths of home healthcare services?
 - What are the problems, limitations, or challenges you face in using home healthcare?
 - What are the enablers for this mode of service delivery?
 - Do you have recommendations to improve home healthcare services in India?
 - What can the government do to improve home healthcare services?

If the respondent knows about anyone else who is using/providing home healthcare services, then, inquire if it would be ok to contact them for the purpose of the study and request for their contact details.

Is there anything more you would like to add?

Thank you for your time.

Interview guide of Providers

<u>Providers</u> are people who provide home based healthcare services at patients' homes; appointed directly by the patients or employed with institutions delivering home healthcare services. They include:

- People who may have learnt on the job; or
- Trained but unlicensed personnel i.e. skilled personnel, who have received training as part of a formal course that may be affiliated or recognised by the Government of India; or
- Professionally qualified and trained, licensed providers, registered with professional council/commission.

Exclusion criteria: Providers do not include household members, hired help mainly assisting with activities of daily living, and community-based health workers/volunteers who make home visits as part of outreach activities or community-based programmes.

Thank you for taking the time to meet with me today. I would like to talk to you about your experiences delivering home healthcare services.

Theme 2: Profile of home healthcare providers

1. Can you please tell us about yourself and your role in delivering home healthcare services?

Name of the respondent, Age, Sex, Education:

- Professional qualification/training, duration of course/training (certificate, diploma, degree etc.)
- In the case of trained but unlicensed personnel, enquire about the eligibility criteria and the process for applying to this course?
- Ask for details about the training organisation. Does the training organisation provide practical training at home or hospitals, does it provide job opportunities for candidates after the training?
- Registration with a professional council/commission?
- How many years working in this field?
- Are there any opportunities for career progression and skill enhancement?

Theme 1: Scope of home healthcare services

- 2. Could you please tell us about the services that you provide at the home of patients?
 - What are the common health care needs of the patients?
 - What are the home health care services that you provide?
 - What is the profile of patients-age, sex, socio-economic status, family structure?
 - Has there been an increase in the use of any particular service or type of patient? Are there any services that should be provided in home care but are currently not part of it?
 - According to you, demand for which services is likely to increase in the coming years.

Theme 3: Interaction between patients, providers, and organisations engaged in home healthcare

- 3. Could you please share your experience of working with (name of the) institution?
 - What is your current position in the institution and what activities are you mostly involved in?
 - What process was followed by the institution for your recruitment? Does the institution have any recruitment process or engagement with training organisations that provide trained staff?
 - Did the institution carry out your background check, verify your qualification, documents etc. before hiring?
 - Were you provided with any training by the institution at the time of hiring?
 - Do you have an employment contract? What does it cover-job responsibilities, remuneration, leave details, increment, other benefits, etc.?
 - What are the other healthcare staff providing home based services in your institution? Ask details about their qualification and nature of employment
- 4. Could you please describe your engagement with the patients?
 - How do you come in contact with the patients? How is the patient's condition diagnosed and treatment modality decided? What is your role in that?

- Do you work as part of a team of providers for a particular patient or individually? Please elaborate.
- How is your timing, duration and frequency of service decided?
- Is there any service contract between the patient and you? If yes, please explain who drafts the contract, decides the terms of contract?
- 5. How do you ensure continuity of care for patients between home and institutional care (such as hospitals, rehabilitation centres, day care centres or old age homes)?
 - Where do you refer the patient in case of emergency?
 - Any support is provided in cases of referral, such as arranging for transportation, informing the referral hospital etc.?
- 6. If you have any complaints about the patient's/family's behaviour or the working conditions at a patient's home, who do you talk to about it? Is there any mechanism to resolve such issues? Can you please share an example of any such incident and how was it dealt with? (If the respondent does not share about their own experience, ask if they know of a colleague who may have had such an experience)
 - If the patient has any problem with the home care provider, to whom can they complain? What is the mechanism to handle such complaints from patients? Can you please share an example?
- 7. What measures do you take to ensure the safety of patients and your own safety?
 - What are the arrangements for food, water, toilet, rest/sleep when you provide services at someone's home?
 - Does anyone monitor your work and provide supportive supervision? Please elaborate (ask for examples)
 - 8. What is the mode of payment for your services and who decides about the cost of home healthcare service?
 - Do the patients pay directly to you or does the organisation pay you?
 - Do you get your salary/ payment timely and as per your contract?
 - Does your organisation (or private home health agency) sell pre-decided home healthcare packages? Ask details- what type of charges are included in home healthcare service package, e.g., cost of care would include consultation charges for each visit by a doctor, physiotherapist, cost of services, drugs, and consumables, etc? or cost of single service or packages that include certain services for defined hours, days, etc.
 - Are there any insurance packages or government schemes that the patients use to finance home healthcare?
 - If the respondent mentions the name of any specific health insurance, ask for details of the insurance benefit, who/what is covered or excluded, payment mechanism.
 - Are there any challenges in using insurance to cover home healthcare? Please elaborate. Ask for examples of when it worked well and when it did not work well.
- 9. Are you aware of any law, or government scheme or programme related to home healthcare services? Eg. National Programme for Health Care of the Elderly, National Policy for Senior Citizens, National programme for Palliative Care etc.
 - If they mention any, request to describe how do they affect their work or home healthcare in general?
- 10. What do you think about the scalability and usefulness of home healthcare services in India?
 - What are the benefits and strengths of home healthcare services?
 - What are the problems, limitations, or challenges that you face in this sector?
 - What are the enablers for this mode of service delivery?
 - Do you have any recommendations to improve home healthcare services in India?
 - What can the government do to improve home healthcare services?

Do you know anyone else who provides home based healthcare services? Are there any patients/users of home healthcare you know of? (If respondent knows, inquire if it would be ok to contact them for the purpose of the study and request for their contact details)

Is there anything more you would like to add?

Thank you for your time.

Interview guide of Managers and Administrators

<u>Managers and Administrators</u> of the organisations such as nursing homes, NGOs, corporate hospitals, home health agencies that provide home healthcare services and provide services in Delhi NCR.

Thank you for taking the time to meet with me today. I would like to talk to you about your experiences delivering home healthcare services.

Background Information

1. Can you please tell us about yourself and your role in the institution, particularly with regard to home healthcare services?

Name of the respondent, Age, Sex, Education:

- What is your current position in the institution?
- Since when have you been working here?
- What activities are you mostly involved in?
- Any other information?

Theme 1: Scope of home healthcare services

- 2. Can you please tell us about the services that are currently delivered in the patient's home through your institution? (please use the name of the organisation/agency)
 - What are the common health care needs of the patients?
 - What types of healthcare services does your organisation provide?
 - Which are the most commonly sought after services?
 - Has there been an increase in the use of any particular service or type of patient?
 - Are there any services that should be provided in home care but are currently not part of it?
 - According to you, demand for which services is likely to increase in the coming years?

Theme 2: Profile of home healthcare providers

- 3. Can you please tell us who are providing home healthcare services through your institution?
 - Please name the types of providers such as doctors, nurses, physiotherapists, non-medical persons etc.
 - How many providers are currently working/associated with you?
 - What is their qualification and training, age range?
 - Are they registered with professional council/ commission?
 - Ratio of male-female providers? Is there difference in demand for male/female providers?
- 4. Are the providers you hire given any training by your institution? Please elaborate.
 - What types of training/courses are offered? Eligibility, duration, trainers, examination, etc.?
 - What is the strength of a batch, how many people do you train each year?
 - Are these courses recognised by GoI?
 - Do you require any permission for conducting these training programmes? If yes, from whom?

Theme 3: Interaction between patients, providers, and organisations engaged in home healthcare

- 5. Can you please elaborate on the process of recruiting home healthcare providers?
 - How do you hire different types of providers doctors, nurses, home health aides, geriatric aides?
 - Is there any recruitment process or engagement with any training institutions that provide trained staff?
 - Is there any need to bring uniformity across institutions delivering home health care courses? Why? Please elaborate.
 - Do you carry out any screening/background checks of the provider before you hire them? Do you check the registration of doctors, nurses, physiotherapists in respective commissions/ councils before employing them?
 - Is there any employment contract that details their responsibility, remuneration, leave details?
 - How is the quality of providers' work monitored?
 - Are there any opportunities for career progression and skill enhancement?
- 6. Considering the different services and providers in your institution, can you please describe the manner of interaction between the patients and the providers? For example,
 - How do the patients contact you?

- How do you diagnose the condition and decide the treatment modality? e.g. Are there protocols for caring for different conditions? What are these protocols based on- eg. standard treatment protocols set by the government/private bodies like NABH etc? Do you deploy individual providers or a team of providers for a patient, does it differ by the patient's condition, please elaborate?
- How is a provider's timing, duration and frequency of service decided?
- Is there any formal service contract between the patient and the provider? If yes, please explain.
- 7. What measures have you put in place to ensure the safety of the patients and healthcare providers at patients' homes?
 - Is there any screening conducted of the patient's house before deploying a provider?
 - What are the arrangements for food, water, toilet, rest/sleep for the providers at patients' homes?
 - What is the mechanism to handle complaints from patients or service providers?
 - How do you manage these complaints? Ask for examples.
- 8. How do you ensure continuity of care between the patient's home and institutional care (such as hospitals, rehabilitation centres, daycare centres or old age homes)?
 - Where do you refer the patient in case of emergency?
 - Who can refer the patients?
 - Is any support provided in cases of referral, such as arranging for transportation?
 - Ask for examples.
- 9. Can you please tell us about the costing of services?
 - What type of charges are included in home health care packages, e.g., cost of single service or packages that include certain services for defined hours, days, etc? or Cost of care would include consultation charges for each visit by a doctor, physiotherapist, cost of services, drugs, and consumables, etc?
 - What is the mode of payment for your services? Do the patients pay directly to the organisation or the service provider?
 - Are there any insurance packages or government schemes that the patients use to finance home healthcare?
 - If the respondent mentions the name of any specific health insurance, ask for details of the insurance benefit, who/what is covered or excluded, payment mechanism.
 - Are there any challenges in using insurance to cover home healthcare? Please elaborate. Ask for examples when it worked well and when it did not work well.
 - 10. Can you please tell us about what types of government approval are required to start your organisation?
 - For example, are you registered under Clinical Establishments Act, 2010 or Societies Registration Act, 1860 or Companies Act, 1956?
 - Do you need to comply with labour laws such as the Code of wages Act 2019, Shops & Establishments Act, any other law?
 - In your opinion, do you think government approval or registration is required for institutions to deliver home healthcare?
- 11. Are you aware of any government schemes, policies or programmes related to home based healthcare services? Eg. National Programme for Health Care of the Elderly, National Policy for Senior Citizens, National Programme for Palliative Care etc.
 - If they mention any, request to describe how do they affect their work or home healthcare in general?
- 12. What do you think about the scalability and usefulness of home healthcare services in India?
 - What are the benefits and strengths of home healthcare services?
 - What are the problems, limitations, or challenges that you face or are present in this sector?
 - What are the enablers for this mode of service delivery?
 - Do you have recommendations to improve home healthcare services in India?
 - What are your expectations from the government to improve home healthcare services in India?

Is there anything more you would like to add? Thank you for your time.

Interview guide of Training organisations

<u>Training organisations</u>: Representatives of the organisations who are engaged in the training of home healthcare providers. This may include (but is not limited to) the National Institute of Public Health Training and Research, Healthcare Sector Skill Council, Rehabilitation Council of India, National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, Tech Mahindra SMART Academy, Indian Red Cross Society.

Thank you for taking the time to meet with me today. I would like to talk to you about your experience in training home healthcare providers.

Background Information

1. Can you please tell us about yourself and your role in the institution, particularly with regard to the training of home healthcare providers?

Name of the respondent, Age, Sex, Education:

- What is your current position in the institution?
- Since when have you been working here?
- What activities are you mostly involved in?
- Any other information?
- 2. Why did your organisation come up with home healthcare courses?
 - How did the need for training people in such courses arise?

Theme 2: Profile of home healthcare providers

- 3. Can you please explain about the training courses your institution provides specific to home healthcare such as home health aides, geriatric aides?
 - What types of courses are offered? Eligibility, duration, trainers, examination processes, etc.?
 - Are these courses recognised by GoI?
 - Do you require any permission for conducting these training programmes? If yes, from whom?
 - What is the strength of a batch, how many people do you train each year, male female ratio of trainees?
- 4. How do you generate employment opportunities for the trainees?
 - Engagement with other institutions like home health agencies etc.? Please elaborate.
 - Of the people you train, what proportion find employment after the training within 6 months?
- 5. Are there any suggestions for introducing new training courses in home healthcare?

Theme 1: Scope of home healthcare services

- 6. Can you please tell us about the services that the providers you train deliver in the patient's home?
 - What are the common health care needs of patients for which you train the providers? What types of healthcare services do these providers provide?

Theme 3: Interaction between patients, providers, and organisations engaged in home healthcare

- 7. In your opinion, do you think government approval or registration is required for institutions to deliver home healthcare?
 - Is there any need to bring uniformity across institutions delivering home health care courses? Why? Please elaborate.
- 7. What do you think about the scalability and usefulness of training home healthcare providers in India?
 - What are the benefits and strengths?
 - What are the problems, limitations, or challenges that you face or are present in training and employment generation for the trained staff?
- 9. Do you have recommendations to improve the training of home healthcare providers in India?

Is there anything more you would like to add? Thank you for your time.

Annexure III: Government Recognised Home Healthcare related Vocational Courses

	Course name	Ministry	Minimum eligibility	Minimum	Course	Course recognised or
	(year developed)			age (years)	duration	accredited by
1.	Home Health Aide – 2017	Ministry of Health and Family Welfare	Completion of 10+2 with science	NA	Minimum 644 hours of training	Standards in accordance with National Skill Qualification Framework (NSQF)
2.	Geriatric Care Aide – 2017	Ministry of Health and Family Welfare	Completion of 10 th standard	18	Minimum 1000 hours of training	Standards in accordance with NSQF Listed in Healthcare Sector Skill council as 'Adopted qualification'
3.	Home Health Aide Trainee - 2022	Healthcare Sector Skill Council – Ministry of Skill Development and Entrepreneurship (MSDE)	Completion of 8th standard or pursuing continuous education Completion of 10th standard	14	Minimum 420 hours of training	Standards in accordance with NSQF
4.	Home Health Aide – 2013, reviewed in 2021	Healthcare Sector Skill Council – Ministry of Skill Development and Entrepreneurship (MSDE)	Completion of 10 th standard	18	Minimum 1000 hours of training	Model Curriculum and Qualification pack is compliant to National Occupational Standards
5.	General Duty Assistant Trainee - 2022	Healthcare Sector Skill Council – Ministry of Skill Development and Entrepreneurship (MSDE)	Completion of 10th standard or pursuing continuous education	14	Minimum 420 hours of training	Standards in accordance with NSQF
6.	General Duty Assistant – 2013, reviewed in 2021	Healthcare Sector Skill Council – Ministry of Skill Development and Entrepreneurship	Completion of 10 th standard	18	Minimum 1000 hours of training	Model Curriculum and Qualification pack is compliant to National Occupational Standards

7.	General Duty Assistant – Advanced – 2013, reviewed in 2021 • Critical Care • Maternal & Newborn Care • Dialysis • Parturition	Healthcare Sector Skill Council – Ministry of Skill Development and Entrepreneurship	Completion of 10 th standard	18	Minimum 900 hours of training	Model Curriculum and Qualification pack is compliant to National Occupational Standards
8.	Geriatric Care Assistant – 2017	Healthcare Sector Skill Council – Ministry of Skill Development and Entrepreneurship	 Completion of class 12 (preferably (biology) or completion of ANM/ Home Health Aide/ General Duty Assistant/ General Duty Assistant (Advanced) course One year working experience in case of NSQF level 4 certified HHA or GDA or GDA (Advanced) 	21	Minimum 640 hours of training and 860 hours of mandatory on the job training or internship or clinical or laboratory training.	Model Curriculum and Qualification pack is compliant to National Occupational Standards
9.	Nonclinical – Caregiver Mother and Newborn Child Caretaker Elderly Caretaker	Domestic Workers Sector Skill Council – Ministry of Skill Development and Entrepreneurship	Basic literacy and numeracy	18	Minimum 200 hours of training	Model Curriculum and Qualification pack is compliant to National Occupational Standards
10.	Nonclinical – Caregiver Persons with Disabilities (PWDs)	Domestic Workers Sector Skill Council – Ministry of Skill Development and Entrepreneurship	Completion of 10 th standard	18	Minimum 400 hours of training	Model Curriculum and Qualification pack is compliant to National Occupational Standards
11.	Certificate Course on Geriatric Care	Senior Citizen's division of National Institute of Social Defence - Ministry of Social Justice and Empowerment	Completion of 10 th standard	18	Three months, minimum 420 hours of training	Standards in accordance with NSQF

12.	One-Month Course on basic issues in Geriatric Care	Senior Citizen's division of National Institute of Social Defence - Ministry of Social Justice and Empowerment (MSJE)	Service providersNGO functionaries	One m	ionth	Senior Citizen's division of National Institute of Social Defence
13.	Certificate course on Care and Management of Dementia	Senior Citizen's division of National Institute of Social Defence - Ministry of Social Justice and Empowerment (MSJE)	 People willing to work as dementia caregivers Service providers Functionaries of Old Age Homes/ Day Care Centres /NGOs 	Three days	days to 10	Senior Citizen's division of National Institute of Social Defence
14.	Certificate Course on Caregiving – Primary Training	Sahyogi Scheme - National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, MSJE National Institutes - Dept. Of Empowerment of Persons with Disabilities, MSJE	Completion of 8 th standard	Three	months	Rehabilitation Council of India developed the course module
15.	Certificate Course on Caregiving – Advanced training	Sahyogi Scheme - National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, MSJE National Institutes - Dept. Of Empowerment of Persons with Disabilities, MSJE	Completion of 10 th standard or 8 th with primary care associate training completed successfully	Six mo	onths	Rehabilitation Council of India developed the course module

Annexure IV: Curriculum of Vocational training courses

Course name	As per the training module, individuals would be certified to perform the following activities after the successful completion of the training				
Ministry of Health and Family Welfare					
Home Health Aide (2017)	 Assist patient in bathing Assist patient in grooming Assist individual in dressing-up Support patient to eat and drink Assist individual in maintaining normal elimination Prevent and control infection in the home setting Communicate with geriatric/paralytic/ immobile patient and their care givers Enable geriatric/paralytic/ immobile patient to cope with changes to their health and well-being Implement interventions with geriatric/paralytic/immobile patient at risk of falls Act within the limits of your competence and authority Work effectively with others Manage work to meet requirements Maintain a safe, healthy and secure environment Practice Code of conduct while performing duties Follow biomedical waste disposal protocols 				
Geriatric Care Aide (2017)	 Assist patient in bathing, grooming, dressing-up Support patient to eat and drink-orally/assisted feeds e.g., RT Feeds Assist individual in maintaining normal elimination Maintenance of perineal hygiene, Catheter care in catheterized patients Prevent and control infection in the home setting Care of patients with Alzheimer's disease Communicate with geriatric/paralytic/immobile patient and their care givers Enable geriatric/paralytic/immobile patient to cope with changes to their health and well-being Assist paralytic/immobile patient with risk of fall Follow biomedical waste disposal protocols Assist medication care of the immobile/semi or un-conscious patients under supervision/ guidance of Nurse professional or medical in-charge Care of immobile patient's to prevent bed sores and injuries Identify risk factors/events and inform doctor/nurse/family immediately Act within the limits of one's competence and authority 				

	Work effectively with others
	Manage work to meet requirements
	Maintain a safe, healthy and secure environment
	Practice Code of conduct while performing duties
Ministry of Skill Development and En	trepreneurship
Home Health Aide - HSSC (2013,	Assist patient in bathing, dressing up and grooming
reviewed 2021)	Support individuals to eat and drink
•	Assist the patient in maintaining normal elimination
	Maintain proper body mechanics while handling the patient
	Support patients with diverse needs in coping up with their health conditions
	Assist in maintaining nutrition and hydration and elimination needs
	 Promote safety and demonstrate proper usage of personal protective equipment
	 Implement the interventions planned for patients with diverse needs
	 Maintain a safe, healthy and secure working environment
	Follow infection control policies & procedures including biomedical waste disposal protocols
	Follow infection control policies & procedures including biolifedical waste disposal protocols
General Duty Assistant - HSSC	Assist patient in bathing, dressing up and grooming
(2013, reviewed 2021)	Support individuals to eat and drink
, , , , , , , ,	Assist the patient in maintaining normal elimination
	 Transferring patients and their samples, drugs, documents within the hospital
	 Provide support in routine activities of in-patient department
	Carry out last office (death care)
	Maintain safe, healthy, and secure working environment
	Follow infection control policies & procedures including biomedical waste disposal
	Participant is not expected or should not do surgical dressing, hot or cold applications, vital signs measurement, oxygen
	administration, catheterization, medicine administration, Ryle's tube insertion and feeding, tracheostomy care, gastrostomy
	care, handling patient on ventilator handle, patient in emergency and critical care, any task beyond their scope of work unless
	requested by a supervising staff from the healthcare team.
	. equestion of a supervising every from one neutricule countries.
General Duty Assistant -Advanced -	Perform techniques to maintain the personal hygiene needs of a patient
HSSC (2013, reviewed 2021)	Practice infection control measures
	Ability to perform clinical skills essential in providing basic healthcare services
	Promote safety, understand usage of protective devices and precautions to be taken while usage of oxygen
	T

	Perform right methods of bio medical waste management
	 Basic Life Support, Cardiopulmonary Resuscitation, and other actions in the event of medical and facility emergencies
	Good communication, communicate accurately and appropriately
	Demonstrate professional appearance and demeanour
	• Skilled to take care of patients undergoing dialysis, patients in maternal needs with her newborn, or assist nurse in
	critical care unit.
Geriatric Care Assistant - HSSC	
(2017)	• List the basic healthcare needs of ambulatory conscious elderly people, non-ambulatory / bed-ridden frail elderly
	people etc.
	Counsel and manage older persons who are at home, admitted in healthcare institutions
	 Perform techniques to maintain the personal hygiene needs of an elderly patient
	Practice infection control measures
	Perform clinical skills essential in providing basic healthcare to older persons
	• Promote safety, understand usage of protective devices and precautions to be taken while usage of equipment and
	assistive devices
	Perform right methods of bio-medical waste management
	Perform techniques to assist older persons in maintaining their activities of daily living.
	 Basic Life Support, Cardiopulmonary Resuscitation, and other actions in the event of medical and facility emergencies Good communication, communicate accurately and appropriately
	• Take sound decisions regarding hospitalization, or timely referral to other hospitals for various care and recognizing
	their limitations in knowledge and skills in these areas.
	 Reporting signs of severe illness/ deterioration to higher authorities as per timelines
	Participant is not expected/should not do surgical Dressing/Oxygen Administration/Catheterization/Ryle's Tube
	Insertion/Tracheostomy care/Gastrostomy care/Handling patient on ventilator/ handling patient in emergency care and
	act within the limits of competence and authority.