



VOICES FROM THE LAST MILE

Personal narratives of people living
with hypertension in
Tiruvannamalai

TAMIL NADU, INDIA

JUNE 2024



CAG

Citizen consumer and civic Action Group



SINAM

SADAYANODAI ILAIGNAR NARFANI MANDRAM



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ABOUT CAG

Citizen consumer and civic Action Group (CAG) is a 38 year old non-profit, non-political and professional organisation that works towards protecting citizens' rights in consumer and environmental issues and promoting good governance processes including transparency, accountability and participatory decision-making.

ABOUT SINAM

Sadayanodai Ilaigai Narpani Mandram (SINAM) is a non-profit organisation established in 1986 under the Tamil Nadu Societies Registration Act. Rooted in the spirit of service, SINAM aims to address pressing issues such as injustice, illiteracy, poverty, hunger, and gender discrimination. Over the past three decades, SINAM has actively engaged with underprivileged and marginalised communities across 565 rural villages and tribal hamlets in Tiruvannamalai and Villupuram Districts. Through its multidimensional initiatives, SINAM strives to create positive change and improve livelihoods.

ABOUT GHAI

The Global Health Advocacy Incubator (GHAI) uses the power of advocacy to save lives and create healthier futures. Tackling the world's most pressing public health challenges requires strategic advocacy to pass evidence-based policies and to increase and sustain funding. GHAI has spent the last 10 years working alongside civil society organizations to achieve health policy victories covering more than 3 billion people in 36 countries around the world.

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HYPERTENSION - A LOOMING PUBLIC HEALTH CRISIS

Hypertension, a major cause of premature death worldwide, has been identified by the World Health Organization (WHO) as a critical health concern. The WHO has set an ambitious global target to reduce the prevalence of hypertension by 33% between 2010 and 2030. To combat this silent killer, the WHO has released its first-ever report on the global impact of high blood pressure, providing recommendations that emphasize the importance of lifestyle changes. These changes include adopting a healthier diet, quitting tobacco, and increasing physical activity, all of which can help lower blood pressure.

In the broader context of global health and wellbeing, the United Nations General Assembly adopted the 2030 Agenda for Sustainable Development in 2015. This agenda, which includes the 17 Sustainable Development Goals (SDGs), provides a shared blueprint for peace and prosperity for people and the planet, now and into the future. These SDGs represent an urgent call for action by all countries, both developed and developing, in a global partnership. Addressing hypertension is crucial for achieving SDG 3 targets, particularly those related to reducing non-communicable diseases and promoting mental health. Therefore, the fight against hypertension aligns with these goals, demonstrating the interconnectedness of global health initiatives.

INDIA'S EFFORTS ON HYPERTENSION

Often termed the silent epidemic, prevalence of hypertension is growing at an alarming rate in India. Every 1 in 4 Indians has high blood pressure and is at risk of adverse events from hypertension-related cardiovascular disease. Despite this challenge, India's efforts in controlling hypertension have yielded promising results. In a collaborative effort, the Government of India launched the Indian Hypertension Control Initiative (IHCI) to accelerate the delivery of treatment services to the 220 million individuals in India grappling with hypertension. This joint venture involved the Ministry of Health & Family Welfare, the Indian Council of Medical Research, the WHO Country Office for India, and Resolve to Save Lives. By April 2022, the IHCI had successfully enrolled over 2.5 million patients with hypertension across more than 15,000 health facilities. It stands as a significant achievement in our ongoing battle against this Non-Communicable Diseases (NCDs).

On the occasion of World Hypertension Day in 2023, the Ministry of Health and Family Welfare took a momentous step—the launch of the ambitious "75/25" initiative. With the goal of combating NCDs, particularly hypertension and diabetes, this initiative aims to screen and provide standardized care for a staggering 75 million individuals by 2025. By prioritizing the health of several crore Indians, the "75/25" initiative represents a crucial milestone in our nation's fight against NCDs. This marks the most extensive expansion of NCD care in primary healthcare, globally. This underscores the government's dedication to tackling these health challenges and aligns with the global commitment to meet SDGs and achieve Universal Health Coverage.



TAMIL NADU'S STRATEGIES ON HYPERTENSION MANAGEMENT

In 2020, a survey conducted by the Tamil Nadu Health Systems Reforms Project revealed a concerning high prevalence of hypertension (33.9%) among adults in the state. To address this issue, the government implemented significant steps aligned with WHO recommendations for combating hypertension. Launched in 2021, the Makkalai Thedi Maruthuvam (MTM) - (Healthcare at your doorstep) scheme aims to improve early detection of hypertension, enhance healthcare accessibility, and reduce patient out-of-pocket expenses. Home-based screening and doorstep medication delivery by Women Health Volunteers (WHVs) are key components of this program.

The effectiveness of these measures is evident in data released by the Directorate of Public Health and Preventive Medicine. Over the past two years, the scheme has identified a significant number of new cases: 55.1 lakh for hypertension alone and 26.15 lakh for combined diabetes and hypertension. These efforts highlight Tamil Nadu's commitment to improving public health and its alignment with WHO recommendations. However, ongoing monitoring and adaptation remain crucial to ensure these initiatives continue to effectively meet the needs of the population.



MAKKALAI **THEDI** MARUTUVAM

Healthcare at *your doorstep* - how does it work?



IMAGE SOURCE: Sanchita Sharma / © WHO India

In an effort to make hypertension care cross the last mile and into people's homes, the Tamil Nadu government launched the MTM scheme in 2021. Home-based screening for diabetes and hypertension and drug delivery at the doorstep of beneficiaries are two of the important tasks undertaken by the women health volunteers under the MTM scheme. The core of the MTM scheme is based on task-sharing, ie, using the other cadres of health professionals with adequate training and under robust supervision in hypertension healthcare. MTM therefore recruits and trains local women to screen for hypertension (among other medical services they are trained to offer). Identified patients are then referred to higher centres for diagnostic testing and treatment. The treatment then follows a three-month medication protocol.

HARNESSING PATIENTS' VOICES

Health equity is crucial, especially when dealing with NCDs, as individuals with NCDs often encounter challenges stemming from complex interactions involving sociological and biological factors. Their experiences offer valuable insights that can contribute to a deeper understanding of these interactions, their healthcare needs, and specific areas requiring targeted intervention. Towards this, Citizen Consumer and Civic Action Group (CAG) engaged with hypertensive patients receiving treatment in government healthcare facilities, seeking to understand their experience at these public health care centers, the treatment adherence rates, follow-up, availability of medicines and doctors, accessibility to the centers and other related issues . CAG's work with the community gave first hand information on those areas needing improvement, and also precise ways in which this could be done. This observation report is based on CAG's pilot study in the Tiruvannamalai district of Tamil Nadu.





**WHY
TIRUVANNAMALAI?**



A PROFILE OF TIRUVANNAMALAI

Tiruvannamalai is often cited as one of the backward districts in Tamil Nadu, with its significant rural poverty. Consequently, CAG chose Tiruvannamalai as the location for the pilot study as it aimed to understand equitable health services. The study gathered patient perspectives on hypertension treatment, focusing on individuals with hypertension receiving treatment from government healthcare facilities.

Tiruvannamalai, situated in the northern part of Tamil Nadu, is predominantly an agricultural district. Despite its proximity to Chennai (approximately 196 kilometers away), it remains relatively underdeveloped in terms of industrial production. The district has a population of approximately 2,464,875 people, with over 28% belonging to marginalised communities. Tiruvannamalai is renowned for its cultural and spiritual significance, including landmarks such as the Annamalaiyar temple, Annamalai hill, Girivalam (the monthly circumambulation of the hill), and the Karthigai Deepam festival. Additionally, the world-famous Arani Silk Saree is a prized product of the thriving weaving industry in this region.

Despite being considered one of the poorest districts, Tiruvannamalai plays a crucial role as a major rice producer in the state. Agriculture remains the backbone of the local economy. However, the district faces challenges in terms of literacy rate, ranking low among districts in Tamil Nadu.

உலரி எ எம்பு ஏ ஏணி ஐ ஐஸ் ஒ ஒ

அதர் முதல் எழுந்தெல்லாம் அதி
பகவன் முதற்றே உலகு. ஏன்-1



THE STUDY



OBJECTIVE OF THE STUDY

The main objective of the study is to document testimonials and personal narratives of hypertensive patients receiving treatment in government facilities in the chosen district of Tiruvannamalai, Tamil Nadu. The aim is to gain insights based on their experiences, the impact of policy measures such as extended prescriptions, doorstep drug delivery, and challenges like accessibility to Primary Health Centers (PHC). Additionally, the study seeks to explore obstacles leading to low treatment adherence and issues related to follow-up checks; and create awareness about hypertension care and control among communities, including the youth.



SURVEY METHODOLOGY

CAG, in collaboration with the SINAM NGO in Tiruvannamalai, undertook a survey involving 100 hypertensive patients from villages within the Tiruvannamalai district. These patients, primarily daily wage laborers from low-income communities, were receiving treatment from primary healthcare centres.

We devised and administered an interview questionnaire for the patients, comprising a mix of closed and open-ended questions. This questionnaire aimed to gather information about the patients' demographics, their attitudes towards government healthcare facilities, their ability to adhere to medical advice and their preferred healthcare facilities. For the open-ended questions, the respondents answered in their vernacular language, i.e., Tamil. Those verbatim observations are translated into an abridged English version and presented as quotations in the findings section.

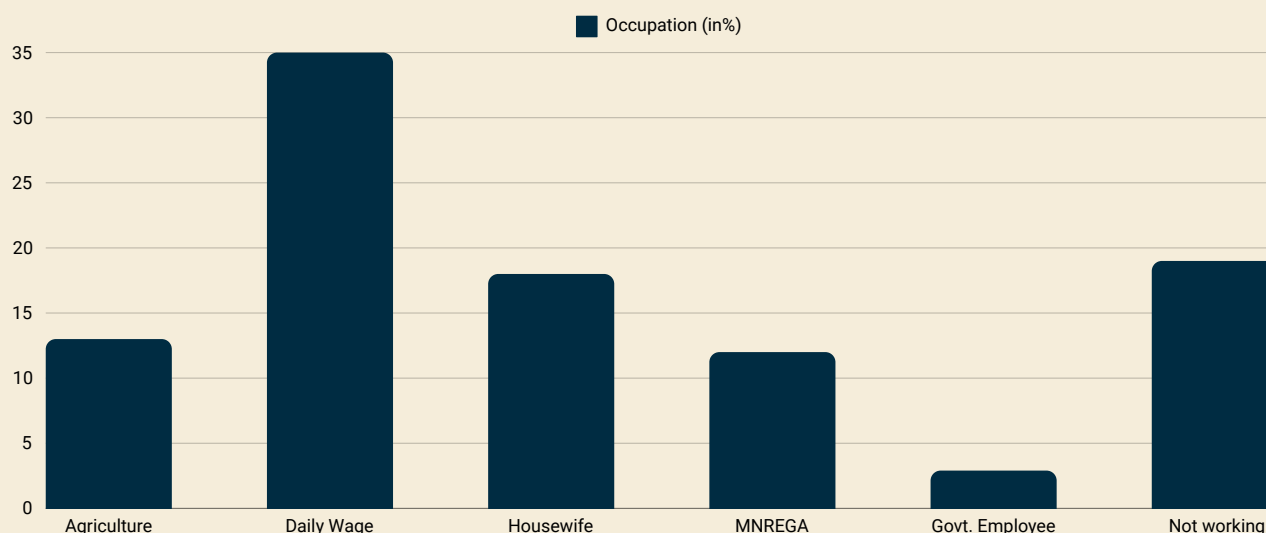
SURVEYED BLOCKS

The survey included three Blocks (Thandampattu, Thiruvannamalai, Mangalam) covering 17 Primary Health Centers - Meyyur Additional PHC, Kattampoondi Upgraded PHC, Pavithram Additional PHC, Palayanur Additional PHC, Anandal Additional PHC, Su.Valavetti Additional PHC, Adiannamalai Additional PHC, Malamanjanur Additional PHC, Sathanur Dam Additional PHC, Vanapuram Block PHC, Perungulathur Additional PHC, Reddiarpalayam Additional PHC, Se.Gudalur UG PHC, Narthampoondi PHC, Thuringapuram PHC, Anandal PHC and Tiruvannamalai Central UPHC.



During the survey, we interacted with NCD staff nurses, who are government employees deployed at the PHCs, as well as front-line workers— WHVs —who facilitate doorstep drug delivery to patients. Their insights significantly enriched our study, ensuring a thorough understanding of patient experiences and the effectiveness of the healthcare system.

DEMOGRAPHICS



Over 60% of the respondents are daily wage and agricultural laborers, and those engaged in the MGNREGA scheme projects. For these individuals, the presence of WHVs providing screening services at their doorstep or workplace and delivering medicines has proven to be highly beneficial. The government's policy of providing assessment and medication free of cost is particularly advantageous to low-income communities.

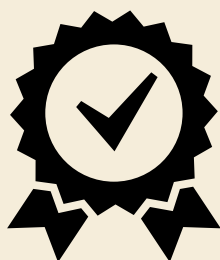


STUDY FINDINGS

1. SEVERAL FACTORS COME TOGETHER FOR THE SUCCESS OF A PUBLIC HEALTH SCHEME



EASE OF ACCESS



QUALITY OF CARE



AVAILABILITY OF MEDICINES

AMONG OTHERS...

It was heartening to note that, overall, the participants were satisfied with the government healthcare facilities and services in Tiruvannamalai which indicates the success of the government's initiatives in dealing with hypertension. However, there were a few concerns that were brought to our notice that indicated there was scope for improvement.

The survey has revealed positive feedback from patients regarding the functioning of primary health centres, particularly in relation to hypertension treatment. The MTM scheme plays a pivotal role in supporting the Government of India's initiative to combat NCDs by 2025. Through the MTM scheme, WHVs have been instrumental in successfully screening and periodically monitoring patients, as well as delivering medicines to their doorsteps.

The collective responses highlight several factors contributing to the success of the healthcare system. These include ease of access, availability of medicine, and quality of service, among others. The key findings that underscore the successful functioning of the healthcare system are as follows:



1.1 FUNCTIONING OF THE PHC WITH RESPECT TO HYPERTENSION

Survey results indicate a high level of satisfaction among participants (97.8%) regarding the functioning of the PHC for their hypertension treatment.

98% 

1.2 AVAILABILITY OF HYPERTENSION MEDICINE

An impressive number of those surveyed (97.8% of respondents) confirmed easy access to their hypertension drugs.

98% 



IMAGE SOURCE: CNN

1.3 HYPERTENSION TREATMENT FOLLOW-UP

Patients reported that hypertension medical care was accessible via the WHVs who form an effective network on the ground, ensuring that otherwise hard to reach populations do not fall through the cracks. According to the survey results, 73.3% of patients receive follow-up calls or intimation from WHVs for their periodic checkups. These volunteers also assist in refilling medicines at people's doorsteps. Patients have warmly welcomed this initiative, as it significantly eases their healthcare management.

VIA HOUSE VISIT

73% 

VIA PHONE

27% 

2. EXTENDED PRESCRIPTION

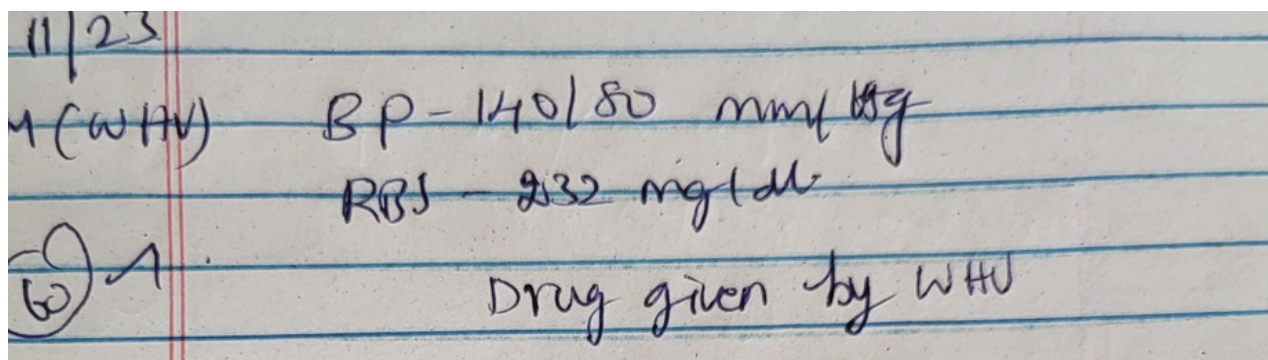
Also, the observation indicates that all participants expressed satisfaction with the medicine distribution process. Patients are instructed to collect a month's supply of medicine from the PHC. The remaining two months' supply is delivered via WHVs. This initiative by the government to ensure extended prescription refills for hypertension aligns with the SDG 3.8, which advocates for affordable essential medicines for all.

"As a chronic hypertension patient and MGNREGA supervisor, I was taken aback when the WHV's NCD screening at our work camp revealed high blood pressure and elevated blood sugars among many of us. Since then, we've become more health-conscious. The doorstep screening and drug delivery under the MTM scheme have been invaluable. It's free, and the regular follow-ups by volunteers have made us more aware of our health. They're like our personal doctors, always there to guide us during emergencies. This routine has seamlessly integrated into our lives",

Rani, 56 years old, MGNREGA supervisor from Usambadi village.



This clearly shows that Tamil Nadu's flagship program is on the right path, progressing towards achieving effective healthcare methods such as doorstep diagnosis and drug delivery. Existing research highlights the feasibility and acceptance of home-based NCD screening services delivered by trained health volunteers. This underscores Tamil Nadu's unique achievement as the only state in India to successfully implement NCD screening on a mass scale.



A SAMPLE PRESCRIPTION

3. CHALLENGES OF HYPERTENSION MEDICATION MANAGEMENT

A significant challenge encountered was the similar packaging of medicines for various treatments. Our survey revealed that 80% of hypertensive patients also had elevated blood sugar levels and were on medication for Diabetes Mellitus and other comorbid conditions.

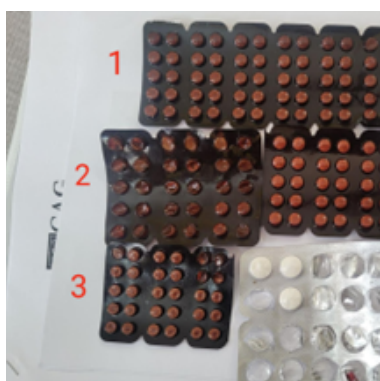
A case in point is the packaging of Atorvastatin 10mg, Amlodipine 5mg, and Glipizide 5mg, which are almost identical with only slight color variations in the medicine strips. Given the patients' literacy levels, they struggle to identify the correct medicines, and the lack of support from the pharmacists at the PHCs exacerbate this issue.

"I believe I'm taking the right medicines daily and feel healthy based on periodic screenings. I don't have extensive knowledge about medicines. If the medicines given to us are of different colors and sizes, they can be easily identified. This would be helpful to many of us, like me, who aren't educated."

Thaamma, 62 years old, daily wage worker from Allappanur village



Consistent with these findings, existing research underscores that elderly individuals are more prone to errors in medication recognition compared to those younger. The most prevalent error is the incorrect assumption of different medicines in identical packages. This error rate escalates to 68% for the elderly and 43% for the young when package colors don't imply different medications. However, a package redesign that prominently displays the substance name on a high-contrast box significantly mitigates these errors. This shows the color component of tablet strips could be a simple yet effective solution.



SIMILAR LOOKING MEDICATION (T. GLIPIZIDE (1), T. ATORVASTATIN (2), AND T. AMLODIPINE (3)) CAUSE CONFUSION



Vasantha, 50 years old, housewife from Allappanur village

"I'm hypertensive and have serious medical ailments. The journey to the hospital is arduous and expensive, but I have no other option. I take my medication regularly and maintain a strict diet to manage my hypertension. Sometimes, my blood pressure increases, but I try hard to keep it under control. Despite receiving free treatment, which supports my financial situation, visiting the hospital for monthly check-ups is a huge burden for me due to the lack of sufficient public transportation."

3.1 NAVIGATING ACCESSIBILITY CHALLENGES AT PRIMARY HEALTH CENTERS

Our survey identified an issue at the Se.Gudalur PHC, which serves the people of Thandampattu and nearby locals. This PHC lacks proper public transportation and is remotely located. Buses operate only at specific times, forcing people to depend on private transportation. Consequently, people find it difficult to visit the PHC and often opt to visit the centrally located Thandampattu Government Hospital for their regular checkups and treatments. This shift burdens tertiary hospitals and undermines the purpose of PHCs.

Public transportation facilities significantly influence patient accessibility to PHCs. Not everyone owns a vehicle, and many rely on public transport. Inaccessible sites might force patients to rely on private transportation, for at least part of the journey. Providing free medical treatment and medications while patients incur substantial transportation costs is counterproductive.

For every 20,000 people, one PHC is assigned to ensure local accessibility. On average, a district block has 6 to 7 functioning PHCs providing medical facilities to villagers. However, the location of the PHC plays a crucial role in its efficient functioning. PHCs, primarily accessed by the low-income community, must be easily accessible by all.

3.2 NCD DAY IS A CONCERN

The survey revealed a significant concern regarding the treatment of NCD at the PHCs. Many PHCs designate one day in a week as 'NCD Day,' requiring villagers to visit early in the morning for routine screenings, consultations, and medication refills.

This process poses a substantial burden on the majority of participants, who are daily wage laborers. The necessity to take time off work forces some individuals to forego their screenings to avoid wage loss. Those prioritising their health are compelled to sacrifice a day's earnings for this follow-up, creating a paradox where free treatment results in financial loss.

This issue is not unique to Tiruvannamalai but is prevalent across the country, undermining the PHC's objective to provide accessible healthcare services at all times. To rectify this, authorities need to devise a system that allows individuals to receive any treatment on any day, thereby supporting the economically disadvantaged and marginalized sections of society. This approach would ensure that no one has to choose between their health and their livelihood.





IMAGE SOURCE: The Hindu

"I am dedicated to the diagnosis and treatment of hypertension and other NCDs. However, the reality of my work differs significantly from what was initially promised during recruitment. I feel undercompensated and lack the necessary infrastructure to carry out my role. Despite these challenges, I remain committed to my role. I urge the government and health authorities to reassess the ground realities and improve our working conditions and remuneration."

3.3 THE **PLIGHT** OF WOMEN HEALTH VOLUNTEERS

WHVs, who tirelessly work on the diagnosis and treatment of hypertension and other NCDs, advocate for improved working conditions, fair compensation, and adequate facilities for frontline health workers. Based on our field work, in addition to their assigned duties, they are tasked with additional jobs that primarily focus on the feasibility of implementing government schemes, yet they are inadequately compensated for these tasks.

It is crucial for the government and health authorities to reevaluate the challenges faced by these volunteers and implement necessary measures to enhance their working conditions and remuneration. This will not only uplift their morale but also augment the effectiveness of health schemes.



CONCLUSION

In this study, we have delved into the lived realities of patients living with hypertension in Tiruvannamalai district. By combining quantitative survey data with personal narratives, we gained a holistic understanding of the healthcare system's strengths and areas for improvement. These include issues related to medication management, such as similar packaging of medicines, accessibility to PHCs, and the working conditions of WHVs. Addressing these challenges is crucial for the success of these initiatives. With continuous monitoring, adaptation, and commitment from all stakeholders, we can strengthen the healthcare system, improve outcomes, and enhance the lives of those living with hypertension in Tiruvannamalai.



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