



Health perceptions and care-seeking practices for non-communicable chronic conditions in a low-income neighbourhood in Bengaluru, India: Lessons for responsive urban health policymaking

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PEAK Urban health research in India was conducted in a low-income neighbourhood in Bengaluru to understand the perception of health and care-seeking practices among individuals diagnosed with non-communicable chronic conditions.

This research brief documents the findings of this research and the possible policy implications to improve prevention, promotion and treatment of non-communicable chronic conditions.

Introduction

The multifaceted nature of healthcare delivery in urban India, dominated by private healthcare providers, affects slum residents' decision-making for healthcare choices. For Indian slum residents their first point of contact for health needs are either qualified or unqualified private healthcare providers who are socially embedded in the slums. Therefore, primary government-provided healthcare services are likely under-utilised in urban India. Studies on health perceptions and care-seeking behaviour in Indian slums in the context of communicable diseases have shown that there are individual, socio-cultural, and economic factors influencing care-seeking behaviour throughout care-seeking pathways and these factors delay diagnosis and treatment significantly. But similar studies, including prevalence-based research, are rare in the context of non-communicable diseases (NCDs) and associated chronic conditions.

The PEAK Urban research project on urban health in India focused on documenting the illness experiences of slum residents diagnosed with non-communicable chronic conditions i.e. diabetes and hypertension, and has attempted to respond to two key questions: How do they perceive being healthy or being ill? And what are their care-seeking practices to adhere to the treatment and medications?

This study was conducted in a low-income neighbourhood, Kadugondanahalli in Bengaluru, Karnataka. This neighbourhood exhibits slum characteristics, with the presence of a recognised slum. The access to healthcare within 1 kilometre's distance from this neighbourhood in relative terms is not a challenge given the presence of primary and community government-provided health centres; enough private healthcare providers, such as nursing homes, primary care hospitals, clinics, and one tertiary care hospital; and diagnostic centres and pharmacies. This multifaceted nature of healthcare delivery especially in Kadugondanahalli and in urban India in general has closed the gap of accessing healthcare services. A total of 20 participants, who were aged above 40 years, from this neighbourhood, consented to participate in this study.

Considering the trends in epidemiological transition and the rise of noncommunicable diseases (NCDs) at the beginning of 21st century, in 2000 the emerging epidemic of NCDs gained prominence in global and national priority agendas. The World Health Organisation (WHO, 2003), in its framework for surveillance of NCDs, clearly depicted the interconnectedness between socio-economic status, risk factors and NCD outcomes. In India, since 2003, NCD surveillance with implementation of the WHO STEPS survey led to improved data collection on prevalence of NCDs and associated chronic conditions and their risk factors. However, after about two decades, sufficient data is still unavailable, as can be seen from the latest SDG India Index 2020–21 (Gol, 2021) where the NCD index was not calculated. A National Programme for Prevention & Control of Cancer, Diabetes, Cardiovascular Diseases & Stroke was implemented by the Government of India (Gol) in 2010 with a focus on strengthening infrastructure, human resource development, health promotion, early diagnosis, management, and referral, which was scaled up to cover the entire country by 2017. Therefore, strengthening of the public health system to address NCDs is in progress but is yet to be fully implemented—as per the data provided by the National NCD Monitoring Survey of 2017–18 (ICMR-NCDIR, 2020)—in terms of ambulatory facilities and facilities for NCDs management, routine screening, and availability of essential technologies and medicines. Therefore, most of the current NCD-related work is focused on curative aspects, i.e., screening and diagnosis, and treatment and its management, and very less attention is given to NCD prevention and promotion.

Policy implications

The health system, in general, highly prioritises the curative approach through diagnosis, treatment and its management over its prevention and promotion. In the case of NCDs, just strengthening the health system's curative care provision through controlling the patient's physiological imbalances (i.e. episodic nature of controlled and uncontrolled hypertension and diabetes) via adherence to the treatment and medications is not enough. The health system has failed to establish a connection with the community in understanding how individuals with non-communicable chronic conditions respond to long-term adherence to treatment and management through care-seeking practices, which, in fact is essential for optimal utilization of government health services for NCDs and associated chronic conditions by the vulnerable and underprivileged groups in urban areas. Further, access to treatment in government health centres is increasingly difficult as there is a lack of available specialised NCD care, at the primary level.

Improving socio-economic and demographic outcomes is essential along with quality treatment and appropriate management in combating the emerging epidemic of NCDs and associated chronic conditions.

Given that long-term adherence to treatment and management of chronic care pushes the financial burden on to individuals/families—especially those belonging to vulnerable and disadvantaged groups—improving both the socio-economic status and modifiable behavioural risks, in addition to controlling the physiological imbalances among individuals diagnosed with chronic conditions, are key to prevention and management of NCDs

and associated chronic conditions. Currently, attention is concentrated on modifying behavioural risks through policy-level interventions without understanding how socio-economic status, as a determinant of health, influences care-seeking practices for chronic conditions and also poses difficulty in initiating and maintaining behaviour change practices such as irregular medicine intake, changes in dietary habits required to control hypertension and diabetes etc.

There is a need for the research and documentation of the determinants and practices that influence seeking of chronic care and the care-seeking pathway especially by the vulnerable and disadvantaged groups.

In its possible responses to key public health challenges in urban areas, the National Urban Health Mission (GoI, 2013) have proposed actions on determinants of health by strengthening the capacity of urban local bodies (i.e. the local governments in urban areas) instead of the health system, raising the question: who should be responsible for the determinants of health? The health system, too, is currently ill-prepared to improve the long-term adherence and management of chronic care by addressing the determinants and care-seeking practices. Further, the multifaceted nature of urban healthcare delivery – i.e. presence of multiple forms of healthcare facilities/providers especially dominated by private providers – also influences the decision-making towards seeking care, which in turn makes the care-seeking pathway complex.

The innovative findings of this study will help strengthen the health system towards treatment and management of chronic conditions and improving the care-seeking pathway in urban areas.

This research found that the care-seeking pathway for chronic conditions is complex given the strong influence of social, economic, behavioural, and psychological factors on health perception and care-seeking practices. These factors lead to either a delay in diagnosis, or sometimes withdrawal from adherence to the treatment and medications. The health system is responsible for only direct examination through appropriate measurement and laboratory-based tests, prescribing and assuring availability of medicines, and advice for behaviour change in physical activity and diet. However, long-term adherence to treatment and medications is found to be beyond these measures, aiming to control the physiological imbalances alone. In the case of chronic conditions, utilisation of government health services is very low, and care-seeking decisions are based more on where they purchase medicines than on the type of healthcare centre they visit.

Research Question 1. How did individuals with non-communicable chronic conditions perceive being healthy or being ill?

The study participants perceive being healthy or ill in an episodic manner while adhering to the treatment and medications for hypertension and diabetes either regularly or irregularly. This state of being healthy sometimes and being ill at other times is influenced not only by the physiological imbalances through the controlled and uncontrolled state of hypertension and diabetes, but also by social, economic, behavioural, and psychological factors.

Findings

This study considered health and illness as different entities given that the study participants—diagnosed with either hypertension or diabetes or both—articulated self-perception of health through the notion of being healthy and being ill. We have defined the notion of being healthy and being ill as “the diseased state of an individual does not inevitably lead to ill-health and that absence of diseased state is also not an assurance for good-health” (Das et al 2020). Though the diseased state is highly influenced by physiological imbalances, this study found that it is also simultaneously influenced by social, economic, behavioural, and psychological factors.

(i) Family support and caregiving were social factors that highly influenced the health status of the study participants. The perception of being healthy and being ill is reflected through the active support and no support, respectively, from family members, especially children. Participants connected no support with their taqdeer (fate). Family support included caring and belonging, accompanying the doctor, purchasing medicines, and, in a few cases, taking care of the entire family. In cases where the participant's child has passed away, or their children did not live with them, the participants would bring a female child from among their children or grandchildren into their house. This led participants to perceive themselves as being healthy as these female children supported the psychological wellbeing of the participants by caring for them in terms of belonging, timely medicine intake, and in other household activities. However, the health, education and wellbeing of these female children is fully supported by and provided for jointly by the participants and the child's parents. Family members perceived the participants as being ill, which led to limiting their parenting, and especially mobility due to higher chances of accidents experienced from physical discomfort and to avoid unnecessary hospital expenditure.

(ii) The economic factors are limited to the participants' involvement in economic activities. The majority of the participants were engaged in informal economic activities, while they had been diagnosed with hypertension or diabetes. Informal work

included: being an electrician, beedi (a type of Indian cigarette) making, incense stick making, basket weaving, domestic work, tailor, hat maker and seller, running a petty shop, and being a barber in men's saloon; whereas two participants were engaged as hospital housekeeping staff and bus driver, which were contractual jobs. Participants articulated the notion of being healthy and being ill by connecting their physical discomfort, such as tension from an accident due to tiredness, tiredness while walking and doing more/heavy work, leg pain, and tiredness while walking under the sun. The diagnosis of hypertension and diabetes or both had a very high influence on overall optimal productivity (including economic and non-economic) which participants articulated as "susst" (tiredness) or "kamjori" (weakness). However, more than half of the participants had stopped their regular engagement in economic activities when the interviews were conducted, and a few of them were engaged but irregularly, or started activities like petty shops in their house premises, especially where mobility is limited.

(iii) Behavioural factors such as maintaining physical activity, following an appropriate diet, and regular and timely intake of medicines were found challenging by the participants. The notion of being healthy and being ill is articulated by comparing the daily lifestyle before and after the diagnosis. For most of the participants, maintaining their regular lifestyle after the diagnosis became harder than before. Participants connected their physical activity mainly with walking during performing household chores, type of occupation, and painful physical discomfort mostly in their legs. Therefore, participants who discontinued their economic activities were hardly affected by walking on a daily basis. A few participants also benefited from

walking, which relieved their discomfort. Further, following an appropriate diet was hindered by the non-preparation of separate food following diet restrictions at home for the majority of the participants, and very few participants got used to following an appropriate diet. Most of the participants avoid eating food not prepared at home. The participant's involvement in economic activities or supporting family members in income-related activities led to irregular meals. Finally, regular and timely intake of medicines is highly influenced by economic reasons, but the behavioural aspect (i.e., the irregular intake of or deciding to stop medications without doctor's advice) is influenced by participants' self-perception of being healthy. However, most of the participants were aware that they should not stop medications for hypertension and diabetes.

(iv) Due to the enormous stress from family problems, financial instability, death of family members, chronic illnesses among family members and daily struggle, almost all participants were going through psychological distress. During the interview, most of the participants cried while speaking about their health, illness and their struggle for attaining good health. The stress is expressed through emotional stress, identified as the main cause of diagnosing hypertension and diabetes as articulated by most of the participants. Being previously aware of hypertension and diabetes—through the experiences of family members, extended family, or neighbours—helped diagnosed individuals experience reduced tension. However, their own diagnosis in the long run contributed to experiencing emotional weakness. In addition, psychological distress is very high when both the participant and their spouse are diagnosed with chronic illnesses.

A family of three members (participant, her husband and their son) live in a semi pucca house [a house without a concrete roof] at Kadugondanahalli, which has a single room without a separate kitchen and irregular water supply. Their son is a young adult (age) and the only breadwinner of the family.

Participant in her own words: "My husband, who was a watchman and left his job, has BP [hypertension]. Sometimes it was normal and sometimes high [based on self-perceived health]. He used to take tablets when it was high but said no need of tablets when it was normal. Suddenly, he had a stroke. Due to financial problems after taking him to three different hospitals, we have stopped going. Now he is partially paralyzed ... [paused due to participant crying] ... wasn't able to do anything for the last two years, can't speak, hear and move hands. Before, he took care of me very well. Currently, I am getting free medicines for both BP and sugar [diabetes], but it is very difficult to get medicines and nutrition syrup, prescribed by the doctor to my husband, due to not having money. It costs about 700 to 800 rupees in the medical shop".

Research Question 2. What were the care-seeking practices that individuals with non-communicable chronic conditions practised?

The study participants had a wide range of complex practices—related to socio-economic, cultural, behavioural and psychological factors—to initially screen and diagnose, and further adhere to the treatment and medications for hypertension and diabetes. These practices positively influence their care-seeking decisions. Further, avoiding healthcare for hypertension and diabetes was also found as a practice in a few instances.

almost all participants continued with self-prescription of medicines for quick relief from the discomfort even after they were diagnosed with hypertension and diabetes. However, they did not get permanent relief and after a significant delay, visited a doctor.

A participant who continues to practise self-prescription expressed, "After I come back home seeing the doctor, I write down in my notebook ... for what health problem did I go to doctor? What medicines were prescribed? etc. Next time when I feel I have a similar health problem, I buy the same medicines as written in the book from the medical shop and take it."

Findings

1. Care-seeking practices before being diagnosed with hypertension and diabetes:

Care-seeking practices showed that early screening and diagnosis of hypertension and diabetes was delayed due to the following four reasons:

(i) Neglecting physical discomfort for mainly behavioural and economic reasons including participation in economic activity at an early stage was reported by the study participants and was managed by purchasing and consuming symptom-specific medicines from medical shops without visiting a doctor;

(ii) Use of home remedies by using warm water and preparing 'power drinks' from the leaves of medicinal plants locally available after recognising the initial discomfort and not seeking immediate care from a doctor. Self-prescription of medicines was also practised by the participants. Almost all the participants had a stock of all necessary medicines that provide quick relief, including the medicines for their chronic illnesses and short-term morbidities. Few participants continued with home remedies, while

(iii) In terms of choice of health facility, the first point of contact for any discomfort was the family doctor. Family doctors are family physicians who practise at a clinic in the slum and provide cheap treatment to residents. For consultations, a visit to the clinic/family doctor is sufficient rather than going to the hospital for the participants.

(iv) Even after recognizing the severity of the discomfort due to decreased productivity and accidents such as fainting spells and immobility having led to visiting a doctor, diagnostic testing especially for diabetes was not prescribed by the doctor due to the treatment of other confirmed diagnosed conditions. More than half of the participants confirmed having been diagnosed with more than one comorbidity including thyroid, cholesterol, asthma, musculoskeletal and eye problems, and stroke. Therefore, almost half of the recruited participants were accidentally diagnosed with hypertension and/or diabetes when tests for these were done randomly while visiting a doctor for severe physical discomfort (thought to be due to a confirmed diagnosis) and other comorbidities including short-term morbidities. Prescription of symptom-specific medicines by the doctor was also reported by study participants.

2. Care-seeking practices after being diagnosed with hypertension and diabetes:

The continuum of care became more complex after the diagnosis, i.e., the initiation of treatment, and continued monitoring, adherence and its long-term management are the two critical components in the continuum pathway that are hindered by the following practices of the study participants.

2.1 Practices based on belief

Care-seeking practices influenced by beliefs led to non-acceptance of the diagnosis, which led to not initiating medication immediately and irregular treatment follow-ups.

Participants connected the non-acceptance of diagnosis with the following:

(i) 'Karma' as they have not done anything to get it, so god would keep them healthy and safe; and it was 'god's wish' in cases where participants changed their behaviour towards diet knowing that they might get hypertension and/or diabetes due to family history and they still got it;

(ii) Traditional practice: A home-based experiment using water—which is used to determine whether one is diabetic or not—became the basis for stopping medication, as it was believed by the participants that the regular consumption of medicines damages the kidneys;

(iii) Non-acceptance of the blood test report (mostly perceived as errors in clinical testing) led participants to visit another diagnostic centre or hospital for re-confirming the blood test;

(iv) Influence of social networks, such as advice by peers, was mostly limited to behaviour change towards diet to avoid the initiation of life-long medications. But, after no improvement, initiation of medications at a later stage led to dependence on medicines and behaviour change towards diet has no or a limited role in management of the chronic conditions. Further advice from family members and extended family

was also shown to positively influence care-seeking, mostly influenced by the knowledge transferred by the older family members regarding various symptoms that led to hypertension and diabetes, screening for hypertension and diabetes at the age of 45 years, and lessons from accompanying with their family member to the doctor.

2.2 Practices based on recognising the discomfort and its severity

Physical discomfort persists in an episodic manner even after the diagnosis. Participants know the connection between the type of the discomfort and the physiological imbalances through the controlled and uncontrolled state of hypertension and diabetes (e.g., headache leads to increased hypertension, dental problem leads to increased sugar level, etc.). Recognising this severity led to visiting a doctor immediately, either a family doctor or to the doctor/facility where treatment is received and/or medicines are purchased.

2.3 Practices based on medicines



Participants purchase medicines from multiple sources to adhere to prescriptions and treatment plan.

Current sources of medicines

1. Independent pharmacies (medical shops)
2. Pharmacies attached with private clinics
3. Pharmacies in government primary/ community/tertiary health centres
4. Pharmacies in private hospitals/ nursing homes
5. Pradhan Mantri Bhartiya Jan Aushadhi Kendra (located in government community health centre)
6. Trust hospital providing cheap/free medicines

For most of the participants, choice of health facility (i.e. to go to a family doctor, government or private hospital/clinic) depends on where they will purchase medicine. And in a few cases, it was also found that the choice of health facility was different for seeking treatment (mostly confined to consultation and testing) and for purchasing medicines. Almost all participants continued to visit family doctors for any health problems, in addition to their preferred choice of health facility for treatment of hypertension and diabetes. Participants considered the following three elements when purchasing medicines:

- (i) Free/cheap or affordable medicines;
- (ii) Suitability of the medicines;
- (iii) Availability of all the medicines (in terms of quantity and number of days) as prescribed by the doctor from one source.

The various practices that the participants practice to purchase and consume medicines are as follows:

- (i) For most of the participants, there is full or partial financial support for medicine received from family members, especially married children. Family members buy and give a

limited quantity of medicine monthly, and the rest was purchased from pharmacies by the participants;

(ii) One participant who was working in a shopping mall received insurance coverage from employee state insurance through which treatment and medications can be availed from affiliated and panelled hospitals. But this type of job was at risk with the onset of the COVID-19 pandemic. The participant lost their job due to the pandemic and shifted to the government community health centre for treatment and purchasing of medicines. Overall, all participants were going through difficult times regarding purchasing and continuity of their medications given their uncertain jobs and financial instability;

(iii) Alternatively participants purchased medicines from the pharmacies using old prescriptions and from preferred treatment centres. Participants who purchased medicines from hospitals had to go through testing to be allowed to purchase medicines from hospital pharmacies in most cases. But in the case of participants visiting clinics (including those visiting hospitals), they irregularly did blood sugar testing for diabetes for reasons of affordability, even when the doctor prescribed the test, and therefore would purchase medicines directly from pharmacies (medical shops) using old prescriptions;

(iv) Participants had to purchase medicines from outside pharmacies (medical shops) in cases where there was not enough stock of medicines available in hospital pharmacies especially in government health centres and trust hospitals providing free or cheap medicines. A few participants also said that they manage their medicines by using those of another family member, mostly their spouse, who has been diagnosed with a similar condition, enough to complete their course of medicines before the next visit to the doctor.

Another important reason that led participants to switch pharmacies is suitability of the medicines. A majority of the participants expressed that medicines mostly purchased from government health centres including Pradhan Mantri Bhartiya Jan Aushadhi Kendra

(sale generic medicines through dedicated sales outlets, also known as Aushadhi Kendra or pharmacies) were not suitable for the participants. A few participants also expressed that medicines purchased from pharmacies (medical shops) were not suitable. The participants explained that these medicines weren't suitable as they were ineffective in controlling their hypertension and diabetes, and led to the participants feeling lethargic, "walking like an alcoholic person", and suffering from more giddiness. Reduced efficacy of the medicines was reported as insulin injections being replaced with tablets and the participants observed no improvement, continued to have low energy, found their sugar being uncontrolled even after taking proper tablets and managing their diet, and had continued discomfort.

case of insulin, it is about storage and practice of using it. A few participants reported that they willingly stopped taking their medication regularly and/or do not follow the dietary advice. One participant increased their insulin dosage from 10ml to 15ml to control blood sugar after eating food which was not advised, such as biriyani, mainly due to increase in physical discomfort. A few participants expressed that changes in taste due to continuous intake of medicines made them eat 'normal food', mostly the food eaten by family members. In addition, it was found that unavailability of basic amenities like a fridge affected the storage of insulin and a lack of clear advice from doctors on how to use the insulin affected how the participants used and stored it.

(v) The low efficacy of medicines could be due to how the medicines are taken, and in the

Insulin storage:

Having been refused by their neighbours to keep insulin vial in the neighbours' fridge, one participant said: "No, I don't have a fridge to store it (insulin vial). I store it in water. There is a small mud pot. I keep it in that. This is the poor person's fridge. I am keeping it like this for two years and I have not told the doctor about this."

Practice of using insulin:

Participant reported: "I went to the doctor and asked why my sugar is not in control even after following proper diet and tablets. The doctor asked how I was taking the (insulin) injection. I said, I remove the bottle 15 minutes before from fridge and then take it. The doctor told me to take the injection within 10 minutes and keep the bottle immediately in the fridge. Otherwise, it will not be effective much to control your sugar. After following this procedure, my sugar was controlled."

(vi) Participants expressed a mixed perception on allopathic and traditional (ayurvedic) medicines. The majority of participants purchased and consumed allopathic medicine. One participant wanted to continue with both allopathic and ayurvedic medicine as consumption of allopathic medicines was leading to losing memory power. Given that switching brands of allopathic medicines did not have any adverse effects, the participant

opined continuing both these types of medicines could be beneficial. Another participant had a completely opposite opinion of using ayurvedic medicine, which did not control the blood sugar and further led to switching to the allopathic medicines. The other participant switched to ayurvedic medicine from allopathic medicine but is currently continuing with both these types of medicines.

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About us

The PEAK Urban programme aims to aid decision-making on urban futures by:

1. Generating new research grounded in the logic of urban complexity;
2. Fostering the next generation of leaders that draw on different perspectives and backgrounds to address the greatest urban challenges of the 21st century;
3. Growing the capacity of cities to understand and plan their own futures.

In PEAK Urban, cities are recognised as complex, evolving systems that are characterised by their propensity for innovation and change. Big data and mathematical models will be combined with insights from the social sciences and humanities to analyse three key arenas of metropolitan intervention: city morphologies (built forms and infrastructures) and resilience; city flux (mobility and dynamics) and technological change; as well as health and wellbeing.

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Our framework



The PEAK Urban programme uses a framework with four inter-related components to guide its work.

First, the sciences of **Prediction** are employed to understand how cities evolve using data from often unconventional sources.

Second, **Emergence** captures the essence of the outcome from the confluence of dynamics, peoples, interests and tools that characterise cities, which lead to change.

Third, **Adoption** signals to the choices made by states, citizens and companies, given the specificities of their places, their resources and the interplay of urban dynamics, resulting in changing local power and influencing dynamics.

Finally, the **Knowledge** component accounts for the way in which knowledge is exchanged or shared and how it shapes the future of the city.

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